

Exploring the Challenges of Facilitating Participatory Action Research with People Living with HIV/AIDS in the Context of Poverty

by

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Abstract

This study describes a Participatory Action Research (PAR) project that was conducted in Masiphumelele (an informal settlement near Cape Town) in 2003/2004 with a group of 5 black, HIV positive people. The original aim of the study was to facilitate an empowerment process aimed at helping the participants find some solutions to their problems. PAR is, however, an unpredictable process that is shaped by the participants and thus often reaches entirely different outcomes from the original goals of the process. This study encountered a number of challenges which necessitated a change in the aims and of the study. The most serious challenge was the withdrawal of the participants halfway through the study due to financial reasons. Because of this, it was not possible to reach the original goal of seeking solutions to the participants problems. The research aims were therefore adjusted to the following:

- To create an opportunity for a group of people living with HIV/AIDS to engage in a participatory process aimed at self-awareness and empowerment.
- To record and analyse this process with the intention of producing insight into the use of PAR in the context of poverty and HIV/AIDS and to identify the challenges involved.

At the stage the participants withdrew, the researcher had conducted 5 focus group discussions, which had been recorded and transcribed. In the focus groups, the participants had described their circumstances and their needs and had started to discuss what problems they would like to address. The researcher achieved closure by negotiating with the participants that she would analyse the data and return to give feedback. Two further focus groups were conducted some time later, at which this feedback was given and the participants were asked to comment on their experience of the process. The participants were also consulted on the utilisation of the findings and they decided that they would like to participate in distributing the findings to their community. A number of recommendations for future PAR studies are drawn from this research. These include recommendations on:

- Engaging people in the PAR process and maintaining their motivation to be involved
- Increasing participant control over the PAR process and facilitation of the group process
- Crossing language and cultural barriers
- Special considerations relating to HIV positive participants living in the context of poverty

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List of Abbreviations and Symbols

List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immune-deficiency Virus
CD4	CD4+ T-lymphocytes
PAR	Participatory Action Research

Abbreviations and Symbols used in Transcription Extracts

GRP	Focus group meeting
R	Researcher
T	Translator
Nx, Nv, Nt, L	Female participants
X	Male participant
Nx: (Eng)	Shows that the participant spoke in English
Nt: (Xhosa)	Shows that the participant spoke in Xhosa
—	Shows that some lines of the extract have been left out
[...]	Words that have been inserted to clarify the meaning of the extract
(LAUGHTER)	Words in capital letters record non-verbal responses e.g. (laughter)

Chapter 1

Introduction

1.1 Introduction

This study describes a Participatory Action Research (PAR) project that took place in South Africa in 2003/2004. The participants in the research were a group of five black, Xhosa-speaking, HIV positive people living in Masiphumelele, an informal settlement near Cape Town. PAR is an unusual research methodology, the purpose of which is not only to produce knowledge, but also to facilitate the empowerment of the participants and enable them to use the knowledge produced to improve their situation (Babbie and Mouton, 2001; Schurink, 2002). PAR is not, however, a simple methodology and there are many challenges involved in the implementation (Cornwall and Jewkes, 1995; Gray et al., 2000). In this study, a number of challenges were encountered. The most significant problem was the withdrawal of the participants from the research, halfway through the process (see Section 1.4 on page 3 for more details). This meant that the research process had to be adapted to accommodate the participants' needs and achieve closure. Other challenges included problems relating to cultural and language barriers which resulted in miscommunication and misunderstandings. This study examines the challenges that were encountered by the researcher in the PAR process and, from this, produces recommendations for future studies. This chapter includes:

- Background to the Study
- Rationale for the Study
- Research Question
- Aims and Objectives
- The Study Context: Masiphumelele
- Theoretical Foundations of the Study
- A Review of PAR Literature
- Overview of the Study

1.2 Background

1.2.1 HIV/AIDS, Poverty and Powerlessness

The HIV/AIDS pandemic has spread rapidly across the world to affect all nations and all sectors of society. Not all groups, however, have been equally affected. HIV/AIDS has been particularly devastating to those sectors of society, which were already marginalised, powerless and vulnerable. People living in the Developing Countries are among the worst affected. In these countries, social conditions, such as poverty, gender inequality and disempowerment, have provided fertile soil for the pandemic and have also magnified the impact of the disease on individuals, families and communities (Van der Vliet, 1996). While not all the issues involved are fully understood, it appears that a critical factor in the pandemic is the issue of power relationships. Those most affected are those who have little control over their lives. They are the most vulnerable to infection and the least able to deal with the consequences of the disease. They are unable to change their lifestyles and do not have the resources to mitigate the consequences of the disease on their lives and their families (Nelson and Wright, 1995; Van der Vliet, 1996). Just as the virus depletes the human body of its natural defences, it also depletes the individual and family of their resources and ability to cope (Lyons, 1998). Van der Vliet (1996) argues that coping with the pandemic has to involve combating these disabling conditions.

1.2.2 HIV/AIDS and Poverty in South Africa

According to UNAIDS (2004), there were approximately 5 million adults and children (out of a population of forty-five million) living with HIV/AIDS in South Africa at the end of 2003. This statistic shows a dramatic increase in the prevalence of the disease since the early 1990s when less than one percent of the population was infected (UNAIDS, 2004). In the light of these alarming statistics, Bradshaw et al. (2003) recommend that urgent attention is given to combating HIV/AIDS in South Africa and point out that other major contributing factors to the spread of HIV/AIDS, such as poverty and gender inequalities, need to be addressed as well. Poverty does not only contribute to the spread of HIV, it also increases the impact of the disease on individuals and their families. Many people in South Africa live in shacks in informal settlements without access to essentials like running water and sanitation and do not have the means to buy nutritious foodstuffs. These conditions make people living with HIV/AIDS more vulnerable to opportunistic infections (Van Niekerk, 2001).

The situation in South Africa is further complicated by the legacy of Apartheid. Apartheid laws denied people, classified in the racial category "non-white" by the Apartheid government, access to good quality education, job opportunities and resources, thus perpetuating the cycle of poverty. In 1994, a democratic government was elected, which has attempted to redress the past imbalances and combat poverty. However, while much has been achieved since 1994, a large number of people are still living in conditions of poverty, without access to basic necessities and with few opportunities to improve their situation (Van Niekerk, 2001). Another major issue of

concern in South Africa is the stigma attached to HIV/AIDS. There is a great deal of ignorance and fear among the general public with regard to the disease and this has led to rejection and discrimination against people living with HIV/AIDS (Orr and Patient, 2004).

1.3 Rationale for the Study

As has been described above, a major contributing factor to the devastating impact of HIV/AIDS is the issue of powerlessness. Not only are the most powerless in society most vulnerable to the disease, but, once they contract HIV, the effect on their lives is to increase their helplessness (Van der Vliet, 1996). The rationale behind this study is based on the need to address these issues of powerlessness and find sustainable solutions for a growing sector of the population - those living with HIV/AIDS in the context of poverty.

There is growing evidence, however, that sustainable solutions for these kinds of problems cannot be found by experts alone. It is necessary for the people to be involved in finding their own solutions (Schurink, 2002). For this reason, this study is based on principles of Participatory Inquiry. It assumes that people have valid experiences and knowledge, which are important for understanding their world and for finding relevant solutions. PAR and other similar Participatory Research methods, have been identified as being important methods that can be used to address issues of powerlessness (Freire, 1997).

While there are a large number of PAR studies, which have been conducted worldwide, in an attempt to address similar issues, the nature of PAR is that it tends to be highly specific to the context in which it is performed and even to the particular individuals and groups who take part in it. It is, therefore, difficult to generalise findings from one context to another and this is why it was decided to undertake a study based in the local community - an informal settlement in Cape Town, South Africa. South Africa has a number of unique circumstances which make it different from other contexts. These include: its history of Apartheid and discrimination, the high levels of crime and violence, poverty and the stigma surrounding HIV/AIDS. Living conditions are even worse for the many people living in informal settlements without adequate shelter and services. These issues compound the impact of HIV/AIDS on individuals and communities in South Africa and make for compelling reasons why studying the issue of powerlessness in this context is not only justifiable, but vitally important. This study also explores the use of PAR in a slightly different context from that of the majority of the studies reviewed in the literature; that is, it focuses on people living with HIV/AIDS on an individual basis as opposed to focusing on a community-based approach. Due to problems encountered in this research, the current study is not able to report on a successful empowerment project. However, the knowledge gained through the process of implementing PAR in the context of HIV and poverty, has produced valuable insights, which can inform future studies.

1.4 Research Question

The initial research question was: "How can people living with HIV/AIDS be empowered to find their own solutions to their problems?" It was intended that this question would be answered through initiating a participatory process in which the participants would firstly, explore their own needs and then look at how they, as a group, could take action against some of the problems in their lives. The group members decided to withdraw from the study, however, before they reached the stage of taking action. (The reasons for their withdrawal are discussed in Chapter Two). As a result of the participants' decision to withdraw, it was not possible to answer the initial research question. Instead the research focuses on describing the challenges that were encountered in the research process. The revised research question is as follows:

"What are the challenges involved in facilitating the PAR process with people living with HIV/AIDS in the context of poverty?"

1.5 Aims and Objectives

1.5.1 Aims of the Study

The aims of the study are as follows:

- To create an opportunity for a group of people living with HIV/AIDS to engage in a participatory process aimed at self-awareness and empowerment.
- To record and analyse this process with the intention of producing insight into the use of PAR in the context of poverty and HIV/AIDS and to identify the challenges involved.

1.5.2 Objectives

- To facilitate a process in which the participants are given the opportunity to take as much control over the PAR process as possible, given the limited time frame of the project
- To engage the participants in a process of self-examination and reflection with the aim of helping them to gain new awarenesses about themselves and their coping skills; and to increase their level of empowerment
- To record the PAR process as experienced by the participants
- To highlight the challenges of facilitating PAR in the context of HIV/AIDS and poverty, and to inform future studies

1.6 The Study Context: Masiphumelele

This project took place in Masiphumelele, an informal settlement situated about 30 kilometres south of Cape Town, in the Sun Valley area. Masiphumelele is a Xhosa word meaning "We will succeed", an apt motto for this small settlement, which has continued to survive in spite of many attempts to demolish it. At the beginning of the 1980s, a small group of about 500 black people settled in the bushes near to where Masiphumelele is situated today. The Apartheid government forcibly moved these families from the area a number of times. They were told that, while they might work in the area, they were expected to live in Khayelitsha, a designated black township, some 30 km away. However, many of these people kept returning to the area, in spite of being repeatedly chased away (HOIKSA, 2003).

At the beginning of the 1990s, with the demise of the Apartheid laws, the people were finally allowed to set up a small community in the area. This community has grown rapidly over the last 12 to 14 years to form a densely populated informal settlement with growing socio-economic problems (Masiphumelele Corporation, 2005). Estimates of the population size vary from 20 000 (Maposa, 2004) to 30 000 residents (Masiphumelele Corporation, 2005), with new residents continually moving into the area. Most of the people are Xhosa-speaking and originate from the Eastern Cape (Masiphumelele Corporation, 2005). Although the area is very under resourced for the size of population it serves, some basic services are provided. Running water, sewerage and electricity are provided to some of the shacks and houses in the settlement and there are two schools, a clinic, a library and a number of churches in the area. Socio-economic problems are rife. These include: unemployment, crime, alcohol abuse and domestic violence (Masiphumelele Corporation, 2005)

Unemployment has been estimated at over 90% (Masiphumelele Corporation, 2005), though this is difficult to calculate accurately, because of the rapidly changing population. In spite of this, people continue to arrive from the rural areas and take up residence in the already overcrowded area, thus stretching scarce resources even thinner. A few people have brick houses, but the majority live in shacks constructed from wood, cardboard and scrap metal (Masiphumelele Corporation, 2005; Maposa, 2004). Shacks are regularly destroyed by devastating fires, which spread rapidly through the overcrowded area, demolishing the readily combustible structures and destroying the homes and possessions of hundreds of people (Maposa, 2003; Dlakavu, 2003).

HIV/AIDS is considered to be a big problem in the area, but it is difficult to estimate its actual impact as many cases go undiagnosed and unreported. This is mainly due to the stigma of the disease and people fearing to be identified as having HIV/AIDS. Prevalence is estimated at between 30 and 40% (HOIKSA, 2003). These figures are significantly higher than the national figures, clearly demonstrating the disproportionate effect of HIV/AIDS on impoverished communities, which has previously been mentioned. The area has a small clinic, which offers general services during office hours, Monday to Friday. After hours, and for more specialised services, residents need to travel by public transport to neighbouring areas. Crime is also a major problem in Masiphumelele and this is aggravated by the lack of a police station in the area (HOIKSA, 2003). A high level of alcohol abuse also contributes to the crime statistics

(Masiphumelele Corporation, 2005).

1.7 Theoretical Foundations of the Study

1.7.1 Empowerment

Empowerment has become a popular phrase in recent times and it is often advocated as the solution for socio-economic problems in society (Mokwena, 1997; Schurink, 2002). However, Mokwena (1997) points out that, while the role of empowerment has been widely recognised in social development, health professionals have lagged behind other professionals and have adopted an autocratic approach in dealing with the health concerns of disempowered communities. Mokwena (1997) proceeds to suggest that empowerment is vital for addressing the health concerns of disadvantaged communities. But what is empowerment and how does one "empower" people to find their own solutions?

Empowerment is a complex concept which is difficult to define and measure (Zimmerman, 1995; Fitzsimmons and Fuller, 2002). As the word itself implies, a key component of empowerment is the idea of increasing power. Schurink (2002, p 407) describes empowerment as:

"The process of increasing personal, interpersonal and political power, enabling individuals or collectives to improve their life situation. Empowerment increases the energy, motivation, coping and problem-solving skills, decision-making power, self esteem, self-sufficiency and self-determination of community members."

From this description it can be seen that the concept of empowerment can include a wide range of skills, attitudes and behaviours. This makes empowerment difficult to define as it may manifest in different ways among different people in different settings and can fluctuate over time (Zimmerman, 1995). Thus it is difficult to draw up a comprehensive list of the skills, attitudes and behaviours that constitute empowerment.

In order to conceptualise the concept more clearly Zimmerman (1995) divides empowerment into three components. These are:

The Intrapersonal Component

The intrapersonal component deals with the perceptions and thought processes that are necessary for empowerment. Without them, the individual is unlikely to have the motivation to take action aimed at overcoming obstacles and achieving his/her goals. The intrapersonal component includes concepts such as perceived competence, a positive self-esteem, motivation to take control of one's life and self-efficacy. Self-efficacy, as described by Bandura (1997, p 4), is "a belief in one's personal capabilities". People with high self-efficacy will tend to think positively and optimistically about the future and believe themselves capable of achieving their goals (Bandura, 1997).

The Interactional Component

The interactional component refers to a person's knowledge of his/her environment and awareness of the obstacles that he/she may come across in trying to achieve his/her goals (Zimmerman, 1995). It includes awareness of the possible options that individuals may have in responding to the challenges of the environment (Zimmerman, 1990a) and the resources that are available. It also involves skills such as leadership and problem-solving (Zimmerman, 1995).

The Behavioural Component

The behavioural component refers to actions the individual takes to improve his/her situation. These may vary greatly from one context to another. Actions may include: joining a support group, attending night school, learning stress management behaviours etc. (Zimmerman, 1995).

Added together, the three components reveal a clear picture of an empowered person who believes in him/herself, knows how to interact with his/her environment and takes part in actions aimed at taking control of his/her situation and in improving his/her circumstances (Zimmerman, 1995).

1.7.2 Participatory Action Research (PAR)

Having highlighted the importance of empowerment in addressing the social issues behind the HIV/AIDS pandemic, the next question to consider is how this process can be accomplished. PAR has proved to be an important tool for addressing issues of powerlessness and the need for liberation (Freire, 1997). PAR involves "collective, self-reflective enquiry that is undertaken to improve a situation" (Koch et al., 2002, p110). The process begins with examination and collaborative enquiry into the lived experiences of the participants. The participants are assumed to have essential and valid understandings and experiences, which are vital to comprehending their world and to bringing about change. From the new insights, which the participants gain into their experiences, the researcher helps to facilitate the planning of action to bring about change (Babbie and Mouton, 2001; Schurink, 2002). Change may come in the form of individual or group empowerment, increased capacity to problem solve, and/or the transformation of organisational structures (Cockburn and Trentham, 2002). The key principles of PAR are described below.

Participation and Participant Control of the Research Process

Babbie and Mouton (2001) describe participation as being the most distinctive characteristic of PAR. In PAR, the participants are seen as partners in the research process and not merely subjects of the study. This means that they are involved in shaping and directing the research and take part in the decision-making process (Cornwall and Jewkes, 1995; Babbie and Mouton, 2001; Schurink, 2002). This has implications for the relevance of the research for

the participants, who decide on the agenda and take ownership of the research findings (Parker, 2000). Participation can lead to the following benefits for the participants:

- It can result in opportunities for the participants to learn new skills, such as, critical thinking, problem solving, negotiation skills etc.
- Learning new skills and participating in problem resolution can lead to increased self-esteem and self-efficacy.
- It can result in increased self-reliance and self-determination (Babbie and Mouton, 2001).

The principles of participation and partnership with the participants also have a significant impact on the relationship between the researcher and the participants. Traditionally, researchers have been in a far more powerful position than the communities with which they work. In PAR, the aim is to level this hierarchical relationship as much as possible, by changing the balance of power in the favour of the participants (Webb, 1991; Babbie and Mouton, 2001; Schurink, 2002).

The Use of Local Knowledge to find Solutions

In PAR, local knowledge is considered a vital component of the research for the purpose of generating an accurate and detailed picture of the local situation. Without it, mere academic knowledge is seen as inadequate in truly understanding the context and therefore generating meaningful and appropriate solutions for the community. PAR aims to promote and strengthen local knowledge, thus acknowledging its importance in understanding and solving problems; and helping the participants to recognise the value of their own knowledge (Babbie and Mouton, 2001). Another important principle of PAR is that knowledge is not generated merely for the sake of extending academic learning. PAR is specifically designed to lead to problem solution and social change (Babbie and Mouton, 2001; Schurink, 2002). This problem solution can occur at an individual, small group or wider community level (Cockburn and Trentham, 2002).

The Action-Reflection Cycle

A key component of PAR is the Action-Reflection Cycle. This cycle involves a circular process of action followed by reflection, followed by further action which is informed by the reflection phase. The goal of this cycle is for the researcher and participants to consciously engage in a process of learning from their actions. These insights are then used to inform the subsequent actions that are taken (Zuber-Skerritt, 2001).

The Goal of Empowerment

The PAR process is intended to be an empowering process as well as to lead to empowered outcomes. An empowering process is one in which the participants' self-efficacy and self-worth are built, through learning new skills, gaining new awarenesses and learning to cope better with

their environment. In contrast, an empowered outcome is one in which the result of the process is a change in the participants' environment, which leads to better living standards (Zimmerman, 1995).

1.8 A Review of PAR Literature

PAR has been employed quite extensively in the study of HIV/AIDS. For example, Kesby (2000) and Mabala and Allen (2002) studied how the community could be engaged in the prevention of the spread of HIV/AIDS. Lindsey et al. (2001) report on a PAR intervention, which engaged the community in developing community-based organisations for caring for people living with HIV/AIDS. However, there appears to be a gap in the literature in the area of individual empowerment in the context of HIV/AIDS and poverty. Some studies were found that focused on empowering individuals to address their personal needs in contexts other than HIV/AIDS (e.g. chronic illnesses (Koch and Kralik, 2001) and disability (Stewart and Bhagwanjee, 1999; Law, 1997)). These studies also deal with chronic conditions and relatively marginalised groups and thus involve similar issues to those raised by the current study. These and other studies are examined in more detail below.

PAR places emphasis on the importance of including the participants in the data collection procedure. Data collection involves gathering information about the participants' lived experiences in the form of words or pictures (Creswell, 1998). In a PAR study, however, the role of data collection is more than just information-gathering. It is intended to be empowering as it gives the participants the opportunity to learn new skills such as critical enquiry, reflection, leadership and research skills (Stringer, 1999; Babbie and Mouton, 2001). Law (1997) and Stewart and Bhagwanjee (1999) describe how participants in their studies gradually took over control of the group process, and the researcher's role changed from that of a facilitator to one of an invited consultant. In the studies described by Cockburn and Trentham (2002) and Mabala and Allen (2002), the participants interviewed each other and other community members as part of the data collection procedure, thus developing new skills.

A number of the studies reviewed made use of focus groups as a means of data collection (Law, 1997; Lindsey and McGuinness, 1998; Stewart and Bhagwanjee, 1999; Koch and Kralik, 2001; Cockburn and Trentham, 2002). Focus groups are useful as a participatory method of data collection, because they allow the participants to interact with one another. They can ask each other questions and build on each others suggestions, rather than just responding to the researcher (Stewart and Shamdansani, 1990). Within the focus group format, different strategies for data collection can be used. Preston-Whyte and Dalrymple (1996) and Cockburn and Trentham (2002) both used drama as part of their focus group activities to stimulate discussion. Kesby (2000) used participatory diagramming. The participants were asked to make diagrams using stones and pieces of card to illustrate their understanding of HIV/AIDS and the socio-cultural factors involved in the spread of the disease.

Most of the studies reviewed used qualitative methods of analysis. Some studies focused more on participant involvement in reflection and identifying issues than on any formal method

of analysis (Preston-Whyte and Dalrymple, 1996; Jagananen and Kortenbout, 1999; Mabala and Allen, 2002). Varying levels of participation were found in the analysis process. In the Cockburn and Trentham (2002) study, the participants were full partners in the research process and, as such, they participated fully in analysis, whereas Law (1997) and Koch and Kralik (2001) did not involve the participants as much. The researchers did the analysis themselves and brought the results back to the group to confirm their findings. In Mabala and Allen's (2002) study in Tanzania, the participants were assisted to do the analysis themselves. They gathered information on issues to do with sexuality and HIV/AIDS by interviewing members of the community. They then grouped the information into themes and categories and presented their findings to the community in the form of drama.

In PAR, the role of data collection and analysis involves more than just producing knowledge; rather it should lead to action (Babbie and Mouton, 2001). Koch and Kralik (2001) describe how their study, involving women with multiple sclerosis, led to action on an individual and a collective level. On the individual level, the participants improved their self-management of their disease, and on a collective level they worked together to improve conditions for people with disabilities by writing letters and lobbying for changes. In Law (1997), the participants formed a support and lobby group as a result of being involved in the research. The participants in Stewart and Bhagwanjee's (1999) study were people with spinal cord injuries. On their own initiative, they decided to work on changing society's attitudes towards people with disabilities by doing presentations at schools, media reports and developing a brochure on their group activities. Preston-Whyte and Dalrymple (1996) describe how the participants in their study (school children in Kwazulu Natal) performed dramas and songs for a community HIV/AIDS open day. The children wrote all the items themselves, transforming the message of HIV prevention into their own words and cultural context. In Jagananen and Kortenbout (1999), the participants, farm workers in KwaZulu Natal, identified a need for more food and better nutrition and established vegetable gardens in response to this need. Lindsey, Stajduhar, and McGuinness (2001) describe a project where community members used PAR methods to develop an organisation to provide home care for people suffering from AIDS.

Many of the studies reviewed, found that the participants experienced improvement in self-esteem and self-confidence (Law, 1997; Koch and Kralik, 2001; Cockburn and Trentham, 2002). In some studies, the participants acquired new skills and competencies such as critical thinking and research skills (Stewart and Bhagwanjee, 1999; Mabala and Allen, 2002; Cockburn and Trentham, 2002). Jagananen and Kortenbout (1999) describe how participants learnt to identify needs, prioritise them and plan appropriate strategies. The participants in Koch and Kralik (2001) improved their ability to manage their illness (multiple sclerosis). In Preston-Whyte and Dalrymple (1996) the participants wrote and performed plays and songs about HIV/AIDS prevention, through which they learnt communication skills and gained self-confidence. Cockburn and Trentham (2002) report that their study challenged the participants' perception that they were not able to change their circumstances and the participants gained a sense of self-efficacy from taking part in the study. Law (1997) report that the participants in their study felt supported by the group interaction and felt less isolated.

1.8.1 The Problems and Challenges of PAR

In the previous section, PAR has been advocated as an important method for facilitating empowerment. However, it is important to note that PAR is not a simple method to implement or an easy alternative to other research methods (Cornwall and Jewkes, 1995). Gray et al. (2000) point out that the nature of PAR and its emphasis on partnership and participant control, creates a number of challenges for the process of implementation. These include: problems in transferring control to the participants, conflicting expectations and agendas, problems in motivating people to engage in the research process, the time required for building partnerships etc. Some of these challenges are briefly explored below.

Gray et al. (2000) highlight some of the difficulties in giving over control to the participants in the PAR process. In their study, the researchers found that they tended to unintentionally take back control from the participants and they had to be constantly vigilant to ensure that this did not keep happening. Gray et al. (2000) also discovered that, at times, the participants put pressure on them to exert more control. Cornwall and Jewkes (1995) point out that participants do not always want control. Cornwall and Jewkes (1995) also highlight the difficulties in persuading people to take part in participatory research. They point out that people may be hesitant to invest time and energy in activities, which may not seem beneficial to them. Alternatively, communities may have unrealistic expectations of what the research process can do for them, and thus while they may initially engage in this process enthusiastically, motivation may dwindle rapidly if their hopes are disappointed (Cornwall and Jewkes, 1995).

Lindsey and McGuinness (1998) found time to be a critical factor in the PAR process. Extended time was needed to build up relationships with the participants and to allow the process to emerge without being hurried or reaching premature closure. Sustainability is another issue of concern. Preston-Whyte and Dalrymple (1996) question how much was achieved on the level of behaviour change in their study. The authors express doubts about the projects continued effect without further intervention. In Jagananen and Kortenbout's (1999) study, only two of the twelve families involved, continued to cultivate their gardens after the study was completed. In Law (1997) and Stewart and Bhagwanjee (1999), the participants took over leadership of the research groups, turning them into support groups. This increased the chances of long-term survival of the projects.

Most of the studies reviewed, reported a good level of success, in implementing the PAR process and bringing about meaningful change. It is important, however, to take note of a couple of factors. Few of the studies reviewed, recorded the process over an extended period of time. As most studies were under a year in duration, it is difficult to assess the long-term impact of these projects. Preston-Whyte and Dalrymple (1996) also point out that few researchers publish their failures as well as their successes.

The combination of poverty and HIV/AIDS is one of the most urgent problems facing South Africa. The studies described above show the great potential of PAR in helping people to gain control over their lives in disabling environments. However, a number of challenges have also been highlighted. In the context of the great need for sustainable solutions to the many problems caused by the HIV/AIDS pandemic, it is believed that this study can make

a worthwhile contribution by analysing the PAR process that was implemented, exploring its impact on empowerment and highlighting the challenges encountered in the process. Although the project did not achieve the initial objective of empowering the participants to find their own solutions, the researcher believes that lessons gained from the experience can inform future studies that implement PAR methodology.

1.9 Overview of the Study

This chapter has introduced the background of the research, the rationale for the study, the research question; the aims and objectives; the study context; the theoretical foundations of the study; and a review of relevant literature. The remaining chapters are as follows:

- Chapter Two - Methodology
 - This chapter outlines the methodology used in the research, including the research design, population and sampling techniques, data collection, analysis, research rigour and ethical considerations.
- Chapter Three - Findings
 - This chapter describes the research process and its impact on empowerment. It also highlights the strengths and the weaknesses of the implementation of the methodology and explores the problems which were encountered in the process.
- Chapter Four - Discussion
 - This chapter focuses on the challenges encountered by the researcher in this study and explores these in the light of the findings from other research projects. It also describes the ways in which other researchers have attempted to deal with these issues.
- Chapter Five - Conclusions
 - The final chapter summarises the findings of this research and presents recommendations for future studies implementing PAR. The outcomes of the study are presented and recommendations for future research are outlined.

Chapter 2

Methodology

2.1 Introduction

In this chapter, the methodology used in the study is described. The chapter includes the following sections: research design, access to the research site, population and sampling, data collection, analysis, research rigour and ethical considerations.

2.2 Research Design

2.2.1 Qualitative Research

A qualitative research design has been chosen for this study, because of its focus on the perspective of the participants and the interpretations and meanings that they ascribe to their world. Flick (2002) asserts that qualitative research designs allow the researcher to explore the subjective experience of individuals and groups, as opposed to quantitative methods that are better suited to measuring and quantifying phenomena. The subject under examination in this study is empowerment and the role of the PAR process in facilitating this experience. Some aspects of empowerment can be measured quantitatively (e.g. outcomes such as skills development and action taken as a result of the process). However, there are significant elements of empowerment that are best understood in qualitative terms. These include: self-efficacy, mastery and motivation etc. These fall under the intrapersonal component of empowerment (Zimmerman, 1995) (see page 6). This study also includes the collecting of data by the participants about their lives and their experience as HIV positive people living in a context of poverty. This kind of data, as well as the data on the empowerment process, was considered to be best collected using qualitative methodology, because of its subjective and experiential nature. Flick (2002) further points out that quantitative methods, because of their emphasis on objectivity and distance of the researcher from the field of study, do not prove suitable for studying social phenomena in their natural context. These methods, therefore, do not allow for the entry of the researcher into the field of study and his/her active participation in the phenomenon under study, as occurred in this project.

2.2.2 Participatory Action Research (PAR)

PAR was chosen as the most appropriate method of addressing the aims and objectives of this research, because of its focus on participation, empowerment and taking action based on the knowledge generated by the research. This study aims to record the PAR process that the researcher facilitated with the participants and to describe the challenges involved. A summary of how the PAR process was implemented in this research is given below.

Implementation of the PAR Process

This study was designed to involve the participants in a PAR process aimed at empowerment and taking action against the disabling circumstances in their lives. The process was based on the Action Research steps described by Stringer (1999, p 18): “look”, “think” and “act”. The steps planned for this research were:

1. The participants would describe their own needs and the circumstances of their lives (based on Stringer’s “look”)
2. The participants would analyse these needs and through the analysis process, a particular need would be chosen (based on Stringer’s “think”).
3. An action plan aimed at meeting this need would be devised and carried out (based on Stringer’s “act”)
4. The participants would then reflect on the process and, through the insights gained from the reflection process, would look at ways to improve on the action taken (a second cycle of “look”, “think” and “act”).

The researcher facilitated a number of focus group sessions with the participants in which the process described above was begun. These focus group sessions were tape-recorded and transcribed and field notes were also made for the purpose of recording the PAR process. However, because of the participants’ decision to withdraw from the research, the PAR process did not go as planned and had to be adapted to accommodate the participants’ needs. The actual process is described below:

1. The participants described their needs and circumstances as planned (“look”)
2. Towards the end of the “look” phase, the participants thought about their situation and their needs (“think”) and decided to withdraw from the research (“act”). (The reasons for this decision are explained in Sections 2.6.3 and 2.6.5 on page 22).
3. The researcher analysed the data gathered and presented her findings to the participants. The participants were then given an opportunity to reflect on the findings and the process they had been through and to give feedback (adapted “look” and “think” steps).
4. They were then invited to make suggestions on how they wanted the findings to be used and to participate in using the findings (an adapted “act” step).

2.3 Access to the Research Site

This study was linked with a Memory Box Training Project, a University of Cape Town (UCT) initiative (see Section 2.4 for further details). The researcher made contact with the Memory Box Training Project leaders and asked for permission to work with the participants in one of their projects which was taking place in Masiphumelele. (The reasons for doing this are explained in Section 2.5.1). Permission to go ahead with the study was granted after the researcher had explained the objectives of the research to the project leaders and given them a copy of the proposal. As a result of linking with the Memory Box Project, which was already established in the community, it was not necessary to gain further approval from the community, other than the participants' consent to take part in the process. (The informed consent process and the ethical implications thereof are described under Section 2.9.2).

2.4 The Memory Box Training Project

The Memory Box Training Project is an initiative aimed at involving people living with HIV/AIDS in a process of recording their life-stories and leaving for their families "intimate reminders of their lives" (Morgan, 2001, p18). The participants in the training (a carefully selected group of HIV positive people) are taught how to facilitate workshops for other people in their community who are also living with HIV/AIDS. In the workshops, the trainee facilitators show the community members how to make their own memory boxes and memory books. Memory boxes and memory books are made out of whatever scrap material is available. The people fill their boxes with significant objects and write stories and draw pictures in their books to provide an illustration of their lives. The aim of the memory boxes and books is to help families and particularly children, to prepare for, and cope with, their impending loss and to ensure that they do not lose the memory of their departed parent or relative. The making of memory boxes and memory books has also been found to be beneficial in creating a safe context for people living with HIV/AIDS to work through the grieving process (Morgan, 2001). The main focus of memory boxes and memory books is not, however, about dying of AIDS - it is about living with HIV. A variety of creative exercises are used to help the participants build up pictures and stories about their lives to place in their boxes and books. The people are helped to identify strengths, abilities and resources as well as weaknesses and obstacles (Morgan, 2001).

2.5 Population and Sampling

2.5.1 Reasons for Linking with the Memory Box Training Project

The current research project used the same participants as were selected for the Memory Box Training Project. The researcher was therefore not involved in the selection process, which was done by UCT staff members, who co-ordinated the project. The reasons for doing this were as follows:

1. The making of memory boxes was thought to be a useful starting point for the process of exploring the participants' needs.
2. It was helpful for gaining access to the community and gaining credibility with the participants. It also sped up the process as the researcher did not have to interview and select suitable participants.
3. It was also anticipated that joining a larger project could potentially increase the benefits for the participants. The Memory Box Training Project is in itself an empowering project as it teaches the participants new skills and trains them to act as workshop facilitators. Thus it was hoped that the combined effect of participating in both projects would lead to a greater level of empowerment for the participants.

Although linking with the Memory Box Training Project did have a number of benefits for the study, it also had some disadvantages. These are discussed in Section 3.8.5 on page 55.

2.5.2 Selection of the Participants

Sampling Methods

The Memory Box Training Project leaders used a combination of convenience and purposive sampling techniques to select the sample group. Access to people living with HIV/AIDS in South Africa is difficult as there is a great deal of stigma surrounding the disease (Orr and Patient, 2004). Access was obtained through approaching Living Hope, a non-governmental organisation (NGO) working in Masiphumelele. For convenience reasons and ease of access, the sample was drawn from the HIV/AIDS support groups run by Living Hope. This meant that people who did not attend the support group were excluded from the sample. This was not, however, problematic to the current study as the study did not need to have a representative sample. The sample group was chosen by interviewing members of the support group to identify those who were suitable for the project. The selection criteria used to select the participants are given below.

Selection Criteria

- Reasonable fluency in English. (This was included as a requirement as, due to a lack of resources, the Memory Box training had to be conducted in English.)
- A schooling level of Grade 10 or above (The schooling level was important as the trainees would require a reasonable level of literacy).
- Openness about HIV status. (This was also important as the group members would be required to take public roles in which they could be identified as being HIV positive).

The selection of the sample was therefore made with a specific purpose in mind; that is, of choosing people that had the skills required for the work they would be doing. It has therefore been referred to as purposive sampling (compare with Creswell, 1998).

Problems in finding Suitable Candidates

The project co-coordinators struggled to find 5 group members who met these criteria. A particularly difficult problem was finding suitable candidates who spoke English fluently. Initially four women were chosen from the support group and the project started in March 2003. At a later stage, a fifth member, the only man, was chosen. He joined the group in May 2003. For the purpose of protecting their identities, the four women will be referred to as Nx, Nv, Nt and L and the man will be referred to as X. The group members had varying levels of competence in English with Nx and X being the most fluent (they served as translators for the other members). The group also varied in their level of schooling; X had passed Grade 12, but the others had only completed Grade 9 or 10. Some were also more open about their status than others. They had all disclosed to some friends and family members, but some were not ready for full disclosure. However, Nx and Nv had made public statements about their status. The five Memory Box training candidates were approached by the researcher and asked if they would like to be involved in the current research. All five candidates agreed.

The Impact of the Selection Criteria on the Generalisability of the Study

The method of sample selection and the exclusions that were made were not problematic to the current study as the researcher was not aiming for a representative sample, but these aspects need to be noted in terms of the generalisability of the study (see Section 2.8.3 on page 28 for further discussion of this).

2.6 Data Collection

Data collection was a process within a process - that is, while the participants took part in the PAR process and gathered information on themselves, the researcher recorded how the PAR process unfolded. Because the focus of this study is to study the PAR process, answering the research question, therefore, involved studying the entire PAR process. Thus data was collected on each step of the process, including procedures that would not normally be considered as a source of data (e.g. the taking of informed consent and giving feedback to the participants). Below, the data collection instruments are described and then a brief summary of the data collection process is given.

2.6.1 Data Collection Instruments

Focus Groups

Focus groups were chosen as a central part of the research design, because of their interactive nature. The focus group format allows the participants to interact with one another, sharing ideas, stimulating one another's thinking, solving problems and making decisions together (Stewart and Shamdansani, 1990; Kitzinger, 1999; Flick, 2002; Chiu, 2003). Thus focus groups

can be used effectively as a tool for transformation and empowerment within the PAR framework (Chiu, 2003).

In this study, eight focus groups were conducted, which lasted, on average, 1 1/2 to 2 hours each (these are referred to as GRP 1-8). There was also a short meeting held one week before GRP1, at which the participants gave their consent to take part in the study (this is referred to as GRP0). The consent-taking procedure has been included in the data, because it forms an important part of the PAR process.

Focus Group Format

The focus groups all followed the same basic format, which included a short introductory phase, a middle phase and a termination phase. These are described below:

- **Introductory phase:** The researcher started each group by asking the participants how they were feeling. She then gave a brief summary of what had happened in the previous session and asked the participants if they had anything to add or had any questions. The researcher then gave a brief outline of what she wanted the group to cover in the session and checked with the participants whether this was acceptable to them.
- **Middle phase:** In this phase, the researcher used a number of questions to initiate discussion. Some of these questions were prepared before the meeting and others were derived from the group discussion. The questions were designed to be broad and thus allow the participants scope to direct the conversation to issues that were of concern to them (see Appendix E on page 109 for a list of the questions).
- **Termination phase:** In this phase, the researcher thanked the group members for their participation and their willingness to share personal painful information. She then negotiated with them concerning the timing of the next meeting before ending the session.

Translation

A translator was employed to translate what the researcher said from English to Xhosa and what the participants said from Xhosa to English. Translation was done in the focus group sessions, usually immediately after the speaker finished speaking. However, in some instances, discussion was allowed to continue in one language and, when there was a natural break in the conversation, the translator gave a summary in the other language.

Tape-recordings and Transcriptions

A tape-recorder was used to record the discussion in GRP1 - 8. (GRP0¹ could not be recorded as the participants' consent for tape-recording the meetings was only given at the end of this

¹The meeting at which informed consent was obtained.

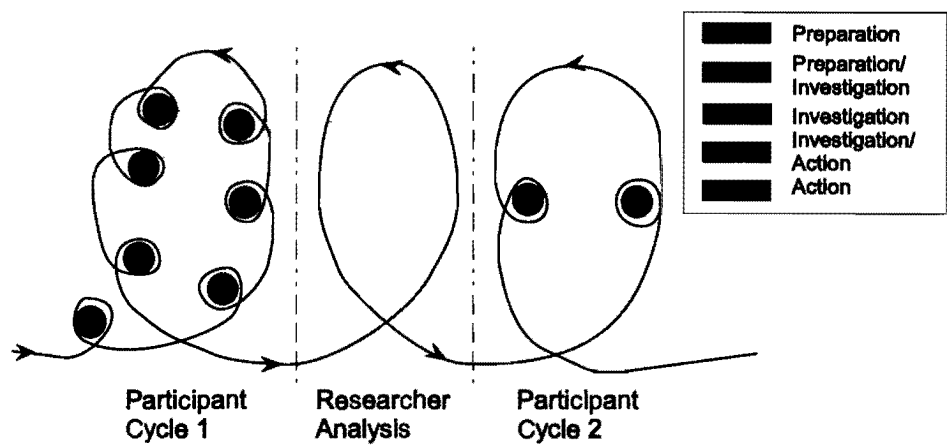


Figure 2.1: Data Collection Process

session). The group sat around a table and the recorder was placed in the middle of the table. The tape-recordings were then translated and transcribed by the translator for the purpose of analysis. The transcriptions were in English, but the translator indicated on the transcriptions, when the participants spoke in Xhosa. (In the section 2.8.1 on page 26 the accuracy of the transcriptions is discussed).

Research Journal

A journal was kept to record all observations and reflections on the PAR process. Entries were made during the planning stage, before the research process started, and then before and after each contact with the participants. These entries were used as supplementary data to the transcriptions to record the researcher's thought processes concerning the planning of the groups and also to record observations and reflections on what happened in the group.

2.6.2 The Data Collection Process

Figures 2.1 and 2.2 on the next page represent the data collection process in diagrammatic form. The figures show the relationship between the Action-Reflection Cycles undertaken in the research, the research phases and the empowerment process. These three components are described in the next section.

The Action-Reflection Cycle

In order to facilitate description, the data collection process has been divided into three main Action-Reflection Cycles. These are named: Participant Cycle 1, Researcher Analysis Cycle and Participant Cycle 2.

- Figure 2.1 shows all three Action-Reflection Cycles, which are represented by 3 large loops. Within Participant Cycle 1 and 2 are a number of smaller loops, which represent

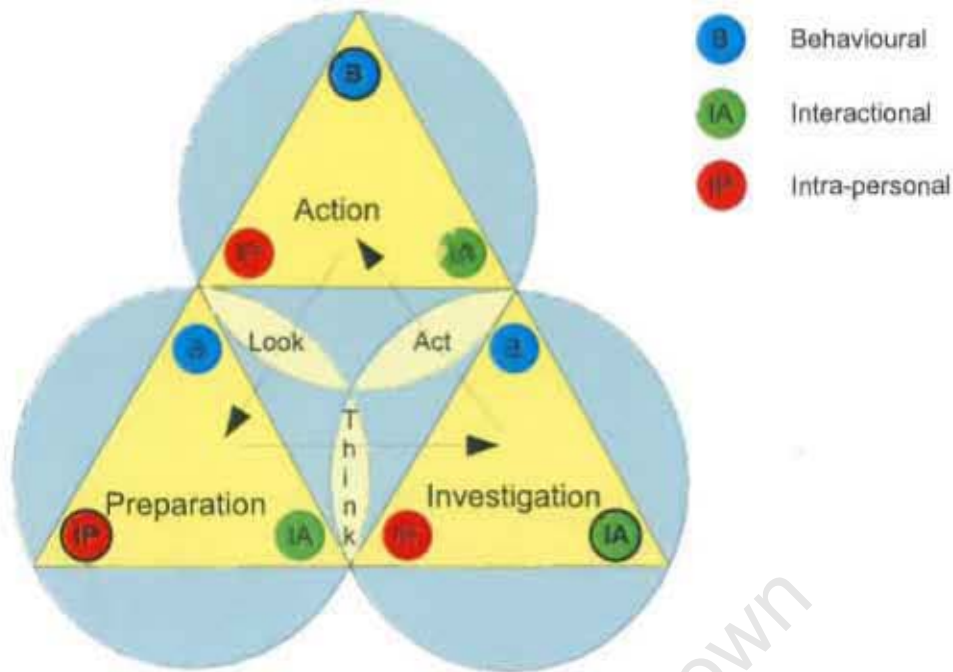


Figure 2.2: The Action-Reflection Cycle

the focus groups (labelled 1 - 8) which were carried out within the cycle. (The Researcher Analysis Cycle does not contain smaller loops as no focus groups were carried out in this cycle). The focus groups are also depicted as being loops in order to show that they are smaller cycles of the Action-Reflection Cycle within the larger cycle. Just before the commencement of Participant Cycle 1, a loop which is labelled 0 is shown. This loop refers to GRP0, the meeting in which informed consent was obtained. It is shown as being outside of the Participant Cycle 1 loop as it was an important preparatory stage to the entire process and needed to take place before the PAR process could begin. GRP1-6 fall into Participant Cycle 1 and GRP7-8 are part of Participant Cycle 2.

- Figure 2.2 shows a more detailed version of a single Action-Reflection Cycle. The Action-Reflection Cycle involves a cyclical process of action and reflection. Stringer's (1999, p 18) steps "look", "think" and "act" are placed in the centre of figure 2.2 to show their central role in the Action-Reflection Cycle.

The Research Phases

The research process has been divided into three phases. These are the preparation, investigation and action phases. The preparation phase can be compared to what Stringer (1999, p 43) calls "setting the stage", a preparatory stage where the researcher establishes relationships with the community and sets up the process. Stringer's "look" and "think" steps have been combined in this research and fit into the investigation phase and the final step "act" fits in with the action phase. In the preparation phase, important processes that were necessary to prepare the participants for taking part in the research, took place. These included: the

signing of consent, forming a group contract, negotiating roles and addressing the expectations of the participants. The investigation phase involved the process of describing and analysing information about the participants' lives in preparation for the next phase, the action phase. The action phase included planning and acting on the information gathered and analysed in the previous phase.

- In Figure 2.1, the research phases are shown by the colours green (preparation), blue (investigation) and red (action). Each of the small loops representing the focus groups, is coloured according to the research phase into which it falls. Groups that fall into more than one phase are shown by one colour merging into another. (The phases in the Researcher Analysis Cycle are not shown as this cycle occurred separately from the participants and thus is not the focus of this research).
- In Figure 2.2, the research phases are represented by the overlapping circles. The circles have been designed to overlap in order to depict how each research phase overlaps with and builds upon the process begun in the previous phases.

Empowerment

The empowerment process is shown in Figure 2.2, where it is represented by triangles. Each triangle contains in its corners, the letters IP, IA and B, which represent the three components of empowerment as described by Zimmerman (1995) (Intrapersonal, Interactional and Behavioural - see page 6). The small triangles within the three circles represent the impact that each research phase has on the empowerment process and the larger triangle made up of the three small triangles, represents the cumulative effect of each of the phases on the overall empowerment process.

2.6.3 Participant Cycle 1: GRP 0 - 6

The research process began in June 2003. Informed consent was taken a week before the focus group sessions began and then GRP 1-6 were held at one week intervals. In this section, the phases of Participant Cycle 1 are described (see Appendix F on page 111 for more detail).

- **Preparation phase (green):** GRP0, GRP1 and the first part of GRP2 fell into the preparation phase. Informed consent was taken in GRP0. In GRP1, important preparatory steps such as defining roles and developing a group contract took place. In GRP2, the preparation phase was completed and the investigation phase was begun.
- **Investigation phase (blue):** The second half of GRP2, GRP3 and part of GRP4 and 5 fell into the investigation phase. In this phase the participants began to describe their circumstances and their needs. Up until GRP2, all the group meetings were attended by all the members, but from GRP3 onwards attendance declined. This was problematic as the process required all members to be present for decisions to be taken. The researcher

asked the participants who attended GRP4 and 5, to ask the others to attend and to contact her if there were any problems.

- **Action Phase (red):** GRP6, as well as part of GRP4 and 5, fell in the action phase. GRP4 and 5 were considered to fall partly into the action phase, because it was at these meetings that the researcher started to discuss with the group how they would like to take action on the information they had gathered. The non-attendance of the group members and their final withdrawal from the process was also considered by the researcher to be part of the action phase as it represents the action that the group members decided to take in response to their needs at the time. In GRP6, the researcher was informed that the group wished to withdraw from the process. The reason given was that two of the group members (X and Nx) had been chosen to be part of a community development project, which would be paying them for their time. Involvement in this project along with the Memory Box Project, would take up most of their time and they were therefore unwilling to continue to be involved in the current study. Of the other members of the group, Nt was in hospital and it was not known when she would be discharged and Nv and L were unwilling to continue by themselves. After hearing this news, the researcher negotiated that she would make a time to meet with the whole group so that the group could make a decision on how to proceed.

2.6.4 Preparation for Participant Cycle 2

The researcher's next meeting with the group was three months later (the researcher suffered from prolonged health problems at this time and this caused the delay). At this meeting, the researcher explained to the group that they had collected useful data and she suggested that a possible way forward would be for her to do some analysis of this data and then come and give them feedback on this. The group agreed to this and it was arranged to meet two months later (this second delay was due to the fact that the participants were going away for the Christmas holidays). In the intervening months, the Researcher Analysis Cycle took place separately from the participants. In this cycle, the researcher analysed the data herself and prepared feedback for the participants. The Researcher Analysis Cycle has not been described in detail as it did not involve the participants and therefore is not relevant to the focus of the research.

2.6.5 Participant Cycle 2: GRP 7 and 8

The third PAR cycle, Participant Cycle 2, took place early in 2004 and consisted of 2 focus groups, GRP7 and 8. In GRP7, the researcher negotiated with the participants on whether they were prepared to be involved in another PAR cycle and the participants gave verbal consent. It was agreed that this cycle would be kept short due to the participants' time constraints. (By this stage, 4 of the group members had found full-time jobs). After re-contracting with the participants, the researcher gave feedback to them on the data that had been collected in the previous cycle. This was done with both pictorial and verbal feedback (see Section 3.7.2 on page 45 for further details). In GRP8, the final meeting, the participants were asked to

give feedback on the positive and negative aspects of the group process according to their experience. At this point, Nx informed the researcher that the main reason they had all withdrawn from the project, was that they had expected to be paid for their time as they had previously been given money by UCT researchers. In the final meeting, the participants were also asked what they would like to do with the results of the study. Once these points were decided upon, the researcher thanked the group members for their participation and the process was officially closed. The participants were each given R100 in recognition of their contribution. (See Appendix F on page 111 for further details on Participant Cycle 2).

2.7 Analysis

Analysis involves making sense of the data that has been gathered (Garner, 1991). The analysis process in the current study consisted of three stages which were conducted at different points in the research process. Each of the three stages were different in terms of their depth, the focus and objectives of the analysis and the analysis techniques that were used. In this section, firstly, the three stages of analysis are outlined and analysis techniques used are listed; and secondly, the analysis techniques are described in more detail.

2.7.1 The 3 Stages of Analysis

Stage 1

The first stage consisted of the analysis which took place in the weeks between each focus group meeting. This occurred in both Participant Cycle 1 and 2. The main objective of this analysis was to inform the next focus group. The researcher therefore concentrated on identifying emerging themes to be explored further at the next group and looking for any potential problems in the process that needed to be addressed. Analysis techniques used in this phase were: immersion in the data and note taking.

Stage 2

The second stage occurred between Participant Cycle 1 and 2. The main objectives of this level of analysis were to inform the next Action-Reflection Cycle and to prepare feedback to give the participants on Participant Cycle 1. The analysis techniques used were immersion in the data and note-taking; coding and categorising; and developing pictorial representations.

Stage 3

The final stage of analysis took place after exit from the research field. This was the most complex level of analysis as it examined the whole research process and was used to address the research question and produce the findings of the study. The analysis techniques used in

this stage were: correcting the transcriptions; immersion in the data; coding and categorising; and developing pictorial representations.

2.7.2 Analysis Techniques

Immersion in the Data

Mason (2002) and Pollock (1991) assert that it is important for the researcher to become very familiar with his/her data. This is done by going over and over the data and thus becoming immersed in it (Creswell, 1998). In the current study, the researcher attempted to do this by listening to the tapes, reading the journal entries and reading through the transcriptions. This was done a number of times at each level of the analysis. On each occasion of going through the data, the researcher focused on different aspects of the data and made notes on relevant insights and themes.

Correcting the Transcriptions

This step took place in the third level of analysis. Silverman (1993) points out that the preparation of transcriptions should not be regarded as merely a mechanical task, but should be regarded as being integral to the analysis process, as it can reveal aspects of the dialogue that were not previously noted. In the current study, the tape-recordings were transcribed by the translator and then the researcher listened to the tapes a number of times in order to correct any mistakes and to record non-verbal features such as silences, pauses and hesitations, laughter and the expression in the voices. Other information such as non-verbal behaviour, the layout of the room etc. was recorded on the transcriptions from the journal entries. As well as improving the accuracy of the transcriptions, this step also served to familiarise the researcher with the transcriptions and thus facilitate the process of becoming immersed in the data.

Coding and Categorising

The objective of coding (also called indexing or categorising) is to organise the data into a form that groups similar themes together and to allow the researcher easy access to the data for the purpose of doing further analysis (Pope et al., 1999; Mason, 2002). Researchers can either use an existing system of coding or categorising or they can derive their own system inductively from the data. Some researchers use a combination of both (Garner, 1991). In the current study, the researcher used some ideas from existing theories on empowerment and PAR to guide the coding process. The theories that were used are listed below.

- Stringer's (1999) steps "setting the stage", "look", "think" and "act" were the inspiration for the development of the research phases: preparation, investigation and action.
- The intrapersonal, interactional and behavioural components of empowerment as described by Zimmerman (1995) were used as a basis for describing the impact of the research process on empowerment.

- The categories knowledge, attitudes and skills, which were used in the second phase of analysis, were derived from Hermanus et al. (2003) (see Section 3.7.2 on page 45).

QSR NUD*IST VIVO² was used to facilitate the coding process. This was done by reading through each of the transcriptions and using the program to code sections of the text. The data was then further organised into groups of related themes or categories. Sometimes these were formed by grouping a number of smaller themes into bigger categories and other times by breaking larger themes down into smaller units. Some codes were renamed in the process and others were discarded as it became evident that they were not useful for achieving the objectives of the process. Different categories and subcategories were used in the different analysis stages in order to achieve different objectives (examples of these are given in Appendix G on page 115).

Developing Pictorial Representations

According to Pollock (1991, p 300) "the task at hand..., in qualitative analysis, is not to describe every piece of the jigsaw puzzle, but rather to stand back and paint a picture of the whole". In the current study, a number of pictorial representations were developed to assist the researcher in the process of "painting the picture". During the process of developing codes and categories, relationships between the various themes became more evident. From these the researcher worked on developing pictorial representations of the data. In the second stage of analysis, three pictorial representations were developed: the "life road", the "shield" and the "cartoon summary". The main purpose of these was to help the participants reflect on what had happened in the previous cycle and to give them feedback on their participation in the process (the pictorial representations and the feedback given are explained in Section 3.7.2 on page 45). At the third level of analysis, a number of tables were used to organise the information and to help the researcher gain an overall perspective of the data. From these tables, the researcher described the overall "picture" of the research findings.

2.8 Research Rigour

Perakyla (1997) divides research rigour in qualitative research into two issues: firstly, ensuring the accuracy and inclusiveness of the data and secondly, testing the "truthfulness" of the findings that are derived from the data. Using more traditional terms, this can be described as establishing the reliability of data and the data collection methods and the validity of the findings. Lincoln and Guba (1985, p 300), however, suggest alternative terms to validity and reliability for establishing the trustworthiness of qualitative research. These are "credibility", "transferability", "dependability" and "confirmability". They suggest that these terms are more appropriate for the naturalistic setting of qualitative research and its focus on the participants' experiences. Below a combination of the two approaches has been used to evaluate research rigour in this study.

²A software package published by Qualitative Solutions & Research Pty. Ltd., 1999. More information is available on <http://www.qsr-software.com>

2.8.1 Reliability of the Data and Data Capturing Methods

A number of issues are important in evaluating the reliability and accuracy of tape-recorded data and transcriptions. Firstly, there is the sound quality of the recordings; secondly, the adequacy of the transcriptions and thirdly, the inclusiveness of the data (Perakyla, 1997).

Accuracy of Tape-Recorded Data

Overall the sound quality of the tapes was good. Each speaker could be identified and in most cases their speech could be accurately transcribed. However, in places there was some loss of data due to background noise, someone speaking softly, or more than one person speaking at a time. The transcriber was instructed to record any occurrences where she could not make out the words. The researcher then listened to the tapes a number of times in order to attempt to fill in these gaps. In GRP7 and 8, the venue for the focus groups was changed. In the new venue, the sound quality of the tapes was much worse and quite a bit of data was lost; therefore GRP7 and 8 were excluded from the analysis process with the exception of some comments that were clearly audible and some observations from the field notes. In the presentation of findings, reference has been made to where data was lost or difficult to hear.

Adequacy of Transcriptions

The researcher listened to the tapes a number of times in order to make the transcriptions as accurate as possible. Silverman (1993) points out that it is impossible to make a transcript completely accurate, but it is important that the data should be sufficiently accurate for the purpose that it is intended. Flick (2002) points out that transcriptions that are used for studying sociological or psychological questions need to be less accurate than those studying linguistic features. It was, therefore, concluded that, as the main message of the speakers came across clearly in the transcriptions, they were sufficiently accurate for the kind of analysis done in the study.

The accuracy of the transcriptions was also affected by the translation process. The translator employed in this research comes from a similar background to the participants. She is HIV positive, comes from a poor socio-economic background and has had no tertiary education. The reason for employing her in this research was to fit in with the ethos of empowerment and give it gave her an opportunity to develop her skills and earn an income. It was also thought that it would be beneficial to employ someone who was HIV positive and from a similar background to the participants as she would be able to identify with them. This did appear to be helpful as the translator developed a good relationship with the participants from the beginning. However, the researcher was concerned that the translator's lack of training might compromise the data. Therefore, in order to determine the accuracy of the translation, the tapes and transcriptions of GRP1-3 were given to another more experienced translator to review. The second translator reported that there were some mistakes in the translation and there were also some passages of dialogue that she was unable to check, because she could not make out the words on the

tape. However, in her opinion, the group discussion was translated and transcribed sufficiently accurately and in sufficient detail for the purposes of this research.

Inclusiveness of the Data

Perakyla (1997) points out that tape-recording as a method of data capture, can leave out certain aspects of the interaction under study and thus impact on the inclusiveness of the data. These aspects include: contextual information about the time and place of the event and the events that happened before and afterwards, and non-verbal and visual information (Perakyla, 1997). Contextual information was gathered from newspaper articles and Internet sources to supplement the tape-recorded data. Field notes made immediately after the focus groups, as well as more detailed notes made not long afterwards, were used to capture other information that was not captured on the tape (e.g. seating arrangements, non-verbal behaviour, events that happened before and after the tape-recorded session etc.).

2.8.2 Credibility

According to Lincoln and Guba (1985), credibility refers to how accurately the findings reflect the reality of the study participants. In this study, triangulation of methods, respondent validation (or member checking) and peer debriefing were used to establish the credibility of the research results. Self-reflexivity was also used as a further method to improve the credibility and rigour of the research. These methods are described below.

Triangulation of methods: The term triangulation refers to the use of a combination of methods to explore the research question (Webb, 1991; Mason, 2002). Mays and Pope (1999) and Mason (2002) point out, however, that while triangulation of methods can be used to make a study more comprehensive and in that way more credible, using it to check different data sources against one another is not considered by these authors, as a helpful way of checking validity. This is because different sources are likely to focus on different aspects of an interaction and thus comparing them can yield confusing results (Mason, 2002). In the current study, triangulation of information was achieved by gathering data from three different sources: tape-recordings, field notes made by the researcher and contextual information gathered from Internet and newspaper sources. The observations made in the field notes were added to the transcriptions to increase the comprehensiveness of the data.

Member checking: Respondent validation (or member checking) involves taking the researcher's findings back to the participants and asking them whether these accurately represent their meanings (Garner, 1991; Mason, 2002). In the current study, the researcher took the preliminary results from Participant Cycle 1 back to the group members and they gave feedback indicating that they recognised their experiences in the descriptions given. However, this feedback was limited due to a lack of time available for the process (see Section 3.7.2 on page 45).

Peer debriefing: Credibility can also be established by asking a colleague to review the analysis process and question the researcher on how he/she came to his/her conclusions. This is

referred to as peer debriefing (Lincoln and Guba, 1985). In the current study, the researcher's supervisor was given the transcriptions to read and she was thus able to point out to the researcher when she had made assumptions about the data that might not be valid.

Self reflexivity: The researcher kept a self reflexive journal in which she recorded her thoughts and feelings about the research process. The journaling process helped the researcher to be more aware of how her own identity, biases and feelings were influencing the study. Through the journaling process, the researcher became aware that she had a need to "fix" the participant's problems and that she felt guilty when she was unable to do so. Once the researcher became aware of these feelings, she discussed them with a counsellor with a social work background. This helped the researcher to work through these feelings and deal with them appropriately and thus resist the temptation to try and take control and attempt to solve the participants' problems for them. The journaling process was, therefore, an important method of ensuring the rigour of the research.

2.8.3 Transferability

Transferability/ generalisability can be established by giving detailed descriptions of the context in which the research took place. This allows the reader to identify similarities to other contexts, and thus apply the results to similar settings (Lincoln and Guba, 1985). In this research, descriptions of the participants are given (see Appendix H on page 119) as well as the context in which they are living (see Section 1.6 on page 5).

2.8.4 Dependability and Confirmability

Dependability and confirmability can be established by keeping detailed records of the analysis process (Lincoln and Guba, 1985). It is important to record what occurred in the research as accurately and completely as possible, not hiding mistakes made by the researcher (Webb, 1991). This process allows the reader to have the maximum possible access to the process used by the researcher to achieve the results that he/she has presented and thus allows the reader to judge the quality of the research for him/herself (Webb, 1991; Mays and Pope, 1999). In the current study, the researcher has attempted to describe the research process, including data collection and analysis, in as much detail as possible and the mistakes made by the researcher have also been recorded (see Section 3.8.3 on page 51).

2.9 Ethical Considerations

The Council for International Organizations of Medical Sciences (CIOMS) (1993, p 10) requires that "all research involving human subjects should be conducted in accordance with three basic ethical principles: respect for persons, beneficence and justice." In this project, a number of processes were put in place to ensure these ethical principles were upheld and the rights of the participants were respected. These are described below.

2.9.1 Accountability

In order to ensure that ethical standards are upheld, the UCT Health Sciences Faculty requires that researchers submit a proposal, which needs to be passed by the Ethics Committee before permission is granted for a study to be carried out. In order to comply with these requirements, a proposal and consent form (including a Xhosa translation) were submitted to the Ethics Committee before the commencement of the study. A copy of the English and Xhosa consent forms and the ethics approval letter is included in Appendices A on page 91. When the participants withdrew from the study and the researcher had to renegotiate entry, the question of whether it would be necessary to submit the proposed changes in the process to the Ethics Committee was considered. However, after consultation with her supervisor, the researcher decided that this would not be necessary, as, although the process had changed, the nature of the interaction with the participants had not changed and the ethical principles outlined in the proposal were being upheld.

2.9.2 Informed Consent

The CIOMS (1993) requires that researchers obtain the informed consent of the participants before the research process is initiated. This is in line with the respect for persons principle as it recognises the individual's right to self-determination. The CIOMS (1993, p 13) defines informed consent as being "consent given by a competent individual who has received the necessary information; and who, after considering the information, has arrived at a decision without having been subjected to coercion, undue influence or inducement, or intimidation". In this study, some challenges were encountered in the process of taking informed consent.

- The first challenge was that of communicating information in appropriate language so that the participants would be able to understand and not be overwhelmed by an overload of detail. This problem was approached by giving the information in a verbal and written form in both Xhosa and English and giving the participants the opportunity to ask questions. The participants were also given a copy of the consent form to take home with them in their language of choice and they were offered the chance to think it over for a week, before deciding whether to sign the form. The participants refused this offer, however, and signed consent immediately. This raises a further question of how appropriate this method of consent-taking is for working with disempowered individuals who may not have the confidence or the skills to ask questions and negotiate with the researcher. This issue is explored further in Chapters Three and Four.
- The second challenge has to do with the nature of PAR, which is an emerging process that develops over time and is strongly influenced by the participants. Therefore, as Meyer (1993) points out, the exact form that the PAR study will take is not known to the researcher at the beginning of the process. As a result, consent in PAR involves the participant agreeing to be part of the process even though he/she does not know exactly where it will lead (Meyer, 1993). Thus, there needs to be a negotiation of trust between

the researcher and the participant. Munhall (1988) suggests that consent needs to be an ongoing process, that is, as new insights emerge and the direction of the study becomes clearer, the researcher needs to re-negotiate consent. Although, only one written consent was taken in the study, the researcher made a point of asking the participants each time a new activity was proposed, whether they agreed with what had been suggested. Consent was also re-negotiated more formally after the participants decided to withdraw and the researcher wanted to organise further sessions to give them feedback. The participants gave verbal consent to taking part in these sessions.

2.9.3 The Right not to Participate

Researchers have an ethical duty not to pressurise people to take part in their research or to offer benefits or incentives that they might not be able to provide, in order to lure people into getting involved (CIOMS, 1993). Cornwall and Jewkes (1995) point out that this presents a challenge for researchers as they need to present some sort of incentive to the participants, which will inspire them to get involved, but not raise unrealistic expectations. In the current study, the researcher was careful to emphasise to the participants that they were under no obligation to take part and that there would be no negative consequences for them if they should decide not to be involved. The participants were also informed that they had the right to withdraw at any stage of the study. In the consent form, the researcher listed the following, as possible benefits that the participants might incur as a result of the study:

1. Development of critical-thinking and problem-solving skills
2. Increased self-knowledge and self-esteem
3. Increased life-skills
4. An opportunity to take action against some of the disabling circumstances in their lives, with the support and backing of the group.

It was emphasised that these benefits could not be guaranteed, but that every effort would be made to make the process as enjoyable and as pleasant as possible. However, the participants actually decided to participate based on a perceived benefit that was not given in the consent form - that of payment. As far as the researcher is aware, nothing was said to give the participants this impression and in fact they were told that there was no funding for the research. This misunderstanding seems to have arisen as a result of the current study being conducted under the auspices of the UCT Memory Box Project (see Section 2.6.5). As the researcher was not aware of this problem until the end of the project, she was unable to address it at the time. However, at the end of the study, before she was aware of the misunderstanding that occurred, the researcher decided to give the participants R100 each as a "thank you" gift. This was greatly appreciated by the group members. (The issue of offering incentives to attract people to take part in PAR is explored further in Section 4.2 on page 59).

2.9.4 Confidentiality

In South Africa, there is a great deal of stigma attached to HIV/AIDS. As a result many people living with HIV/AIDS have been rejected and discriminated against by their families and community (Uys, 2000). This makes the maintaining of confidentiality particularly important in research dealing with people living with HIV/AIDS. In the current study, the confidentiality of the group members was maintained during the research process and no names have been mentioned in this document. Any future publication of the findings will also be done in such a way that the participants cannot be identified. This means that names and references to the participants' circumstances that could give away their identity will either not be mentioned or will be changed. This was stated in the consent form and repeated in the group. In the last focus group, however, the researcher asked the group members whether they would like to have their names mentioned if the findings are published in a magazine or journal article, as it was thought that they might like to be acknowledged for their contribution to the study. Some group members were eager for this to happen and others were reluctant. At the time, it was decided that the researcher would return to the group members to allow them to read any articles she would like to publish so that they could decide whether they would like their names to be revealed in the publication. However, it may not be possible to contact all of the group members and obtain everyone's consent. In this case, the researcher will keep to the original agreement of not publishing the names, as identifying some members could lead to the confidentiality of the others being compromised. (Low et al. (2000) used a similar approach to solve a similar dilemma.)

Kitzinger (1999) points out that research using focus groups can compromise confidentiality as information is shared in a group context. In order to deal with this issue, the researcher proposed to the group that maintaining confidentiality should be one of the conditions of the group contract. All the group members agreed to this.

2.9.5 Risk of Harm

It was anticipated that the participants might find that the intimate sharing of issues around their experience of HIV/AIDS distressing. They were warned of this possibility when they gave consent to take part in this study and they were assured that there would be support and counselling provided to them if necessary. They were also told that they were free to withdraw from the study, if they found it distressing (or for any other reason). During the study, the participants did not give any indication that they were experiencing any kind of emotional distress and no one asked for further support or counselling.

2.9.6 Ownership of the Results and Distribution of the Benefits of the Research

One of the principles of PAR involves ownership of the results being given to the participants. The reason for the importance of this principle is to ensure that any benefits of the research are available to the participants (Babbie and Mouton, 2001). This study is, however, being

undertaken as a Master's dissertation and therefore the results, as written up in this dissertation, officially belong to UCT. This was explained to the participants at the beginning of the process and their consent was obtained for the publishing of the results as a dissertation. It was also explained that any other use of the results would be negotiated with them. The researcher has discussed the possibility of publishing magazine and journal articles with the group and obtained their verbal consent for this. The publication of articles will ensure that the information is made available to professionals, thereby improving services to people with HIV/AIDS and thus indirectly benefiting the participants and the group they represent. Some of the findings were also made directly available to the participants through feedback to the group (see Section 3.7.2 on page 45).

2.10 Conclusion

This chapter has outlined the research methodology used in the study and described the research process. Some of the problems encountered in the research and the way in which these were dealt with have also been mentioned. This chapter, thus lays the foundation for Chapter 3, in which the research process and the challenges encountered in the study are analysed.

Chapter 3

Findings

3.1 Introduction

This chapter analyses the PAR process described in the previous chapter and explores the impact that this had on the empowerment of the participants. It highlights the strengths and weaknesses of the project and identifies a number of challenges which were encountered in the PAR research. The chapter contains four main sections. The first section gives a brief introduction to the participants in the study. The second section gives an analysis of Participant Cycle 1 and its impact on the empowerment process. The third section gives a similar analysis of Participant Cycle 2 and the last section contains an analysis of various other factors which impacted on empowerment.

3.2 Introduction to the Participants

A brief introduction to each of the participants in the study is given below. Although the transcriptions contain rich descriptions of the participants' lives, the introductions given below have been kept short due to the fact that this research focuses on the empowerment process and not the lived experiences of the participants (see Appendix H on page 118 for further details).

L (A 20 year old single woman)

L is the youngest member of the group and the only one who has no children. She has a vibrant, outgoing personality and she was quite vocal in the group. She spoke mainly in English, but reverted to Xhosa when she was battling to get her meaning across. Her English, however, was not that good and she often had to repeat herself. L was diagnosed as being HIV positive just a few months before the research started and thus was at a much earlier stage in the process of coming to terms with her status than some of the others. L attended GRP1, 2 and 5, but missed GRP 3, 4 and 6. She was also unable to attend GRP7 and 8 as she had moved to Khayelitsha to look for work.

Nt (A 23 year old woman with 1 child)

Nt came across as being quiet and shy. Shortly before the research started, Nt lost her second child, a 9 month old baby, who died of an AIDS-related infection. This may have been part of the reason why she was so quiet in the group sessions. Nt could understand a bit of English, but she was the only one of the participants who did not attempt to speak it. She was, therefore, entirely dependant on the translator to interpret for her and this may have discouraged her from contributing to the discussion. Nt was the only married member of the group. However, at the time of the research, she was living on her own as her husband had left her when she told him about her HIV status. (Her surviving child is living with her mother in the Eastern Cape). Nt attended the GRP1-3 and then was absent for GRP4-6 due to illness. (She was in hospital for a few weeks). By the time Participant Cycle 2 started she was much better. She attended GRP7 and 8.

X (A 29 year old man with 2 children)

X was the only male participant in the research. Although X frequently contributed to the group discussion, he did not say as much about himself as the women did and he was reluctant to speak about his feelings. X was quite fluent in English and often assisted the translator. X found out about his HIV status in 2002 when his younger child became sick and both he and the child were tested and were found to be positive. The child's mother had died a few months prior to this, but X had not known that she had AIDS, though he was suspicious. X cared for the child himself until the child became ill and X was forced to put him into a home, where he visits him frequently. X is a family-orientated man, who is deeply committed to providing both for his own children and his younger siblings. Shortly before the research began, X was retrenched from a full-time job with the Navy. This was a huge source of frustration for him as this meant he could not adequately provide for his family. X was the only group member to attend all the focus group meetings.

Nv (A 30 year old woman with 1 child)

Nv did not often contribute to the group discussion, but she had a loud distinctive laugh, which was often heard in the group sessions. She also joined the conversation at times when it was in Xhosa. Her English was better than Nt's, but most of the time she spoke through the medium of the translator. The subject on which she spoke the most was her "sickness". This was a period of time in which she was admitted to hospital, because she was very ill and unable to walk. She was told that she would never walk again and was given a wheelchair. However, as she started to recover, she refused to use the wheelchair and used crutches instead. Eventually she grew strong enough to walk normally again - a great source of pride and triumph for her. She was diagnosed as being HIV positive during this illness period, however, the diagnosis was overshadowed in her mind by the fear of not being able to walk again. Her subsequent recovery did much to help her come to terms with her status. Nv attended most of the focus group sessions, missing only GRP5 and 8.

Nx (A 40 year old mother of 3)

Nx was the most outspoken and enthusiastic member. Her English was much more fluent than most of the other group members and she often helped with translation. Nx is a very proud and devoted mother. She lives with her three children a 21 year old boy, a 19 year old girl and an 8 year old girl - and is very worried about what will happen to them when she dies. She would like them all to finish school before she dies and is determined to look after her health so that she can live as long as possible. Nx attended GRP1-3 and GRP7 and 8. Her presence was greatly missed in the sessions she did not attend as she brought a great deal of vibrancy and enthusiasm to the group.

3.3 Participant Cycle 1

Participant Cycle 1 was the first and the longest of the three cycles. Because of the complexity of the cycle, each of the phases within it, has been divided into a number of steps or processes, to facilitate description. In sections 4.4 to 4.6, the 3 phases and their corresponding steps are described and the impact on the empowerment process is explored.

3.4 Participant Cycle 1: Preparation Phase

This phase was necessary to prepare the participants (who had never done research before) to become researchers of their own experience. The phase has been divided into the following processes:

- Contracting
- Defining Roles
- Addressing Expectations
- Building Trust and "Safe Space"

3.4.1 Contracting

The contracting process was divided into 2 phases: the consent-taking procedure and the group contract. In the first phase, the focus was on the researcher/ participant relationship and the responsibilities which the researcher agreed to undertake in the process. In the second phase, the focus was on the group's relationships with each other and the rights and responsibilities of the members. Key features of these phases are explored below.

Phase 1: Obtaining Consent (GRP0)

At this meeting, the participants were given an explanation of what the project entailed and the possible advantages and disadvantages that might be involved (see Section 2.9 on page 28). To the researcher's surprise and gratification, the participants responded very enthusiastically to the invitation to take part in the study. Unbeknown to the researcher, however, the main reason for the participants agreeing to take part was due, not the listed benefits, but to a misunderstanding - the participants thought they were going to be paid for their time (see Section 2.6.5 on page 22). This unspoken expectation proved to be a key factor, which resulted in the withdrawal of the participants from the research, when they discovered that it would not be met. It, therefore had a critical impact on the empowerment process as, due to their withdrawal, the participants missed out on any further opportunities for empowerment that may have arisen. This misunderstanding also highlights the importance of anticipating unspoken expectations when engaging participants in PAR. People who lack empowerment may not have the confidence or the skills to negotiate for the terms and conditions they would like and therefore special consideration needs to be taken in working with them.

Another issue to consider is the level of participation that the group members took in the consent-taking procedure. Although the participants had been given a lot of information, they did not ask any questions in this procedure, but enthusiastically agreed to take part, refusing the offer to take time to think about it. The fact that they did not ask questions could be attributed to a number of reasons:

- Their enthusiasm over the prospect of earning more money may have distracted them from considering carefully what they were agreeing to.
- Lack of awareness of the need to be careful before signing their consent.
- Lack of awareness of their right to negotiate the terms and conditions of a contract.

According to Zimmerman (1995) critical awareness of the situation is an important aspect of empowerment. In this case it seems that the participants lacked awareness about the contracting procedure and also lacked the skills to negotiate terms agreeable to them. While the approach that was taken to this procedure, was relatively ethically sound and probably not actively disempowering, it appears that an opportunity was lost to be more actively empowering. The participants could have gained more awareness about their rights in the contracting process and learned new skills in how to negotiate these. This raises the question of whether the consent-taking procedure used in this study, which included the use of a pre-prepared consent form, is the most effective way of engaging people who are disempowered in PAR. This issue will be further explored in the next chapter.

Phase 2: Developing the Group Contract

In this phase, the participants took a more active role than in the consent-taking procedure, though some participated more than others. Nx was very quick to respond to the invitation

to make suggestions of terms for the contract and she also made some rather insightful contributions, which seem to indicate that she may have had previous experience of contracting (see Appendix J on page 127). L was the only other group member who contributed terms for the contract, but the others participated in the discussion of some of the other terms, which was done in Xhosa. The lack of participation from the others could have been due to a lack of awareness of the importance of the group contract and/or a lack of knowledge and skills about what should go into a group contract and how terms can be negotiated. As with the previous phase, an opportunity was lost for the participants to learn skills in the contracting process.

One of the objectives in developing the group contract was to encourage the participants to take responsibility for some aspects of the group process. It would have been unethical to put any kind of pressure on them to attend the group sessions and so it was hoped that in the group contract the group would make a commitment to each other. On the surface this appeared to happen to some extent. The participants proposed that if someone wanted to withdraw from the research, they would take responsibility for finding out from that person why he/she wanted to withdraw. If the problem was an internal group problem, they would attempt to solve it; otherwise they would allow the person to withdraw from the group. They also proposed that they would take responsibility for keeping each other up-to-date if anyone missed a group session. (The implication appeared to be that anyone who missed a session should have a valid excuse such as illness, though this was not clearly spelt out). These conditions were discussed in Xhosa by all the group members. Nx also suggested that any problem that they had with the research should be brought directly to the researcher and not discussed behind her back. (The terms of the group contract are summarised in Appendix J on page 127)

On the surface these terms appear to show a willingness to take an active role in the process and to take responsibility for the functioning of the group. However, in practice these terms were not acted upon. The group did not confront the researcher on a major issue that they had - the misunderstanding over payment - nor did they hold each other accountable over attendance or keep each other up-to-date when they missed sessions. It is possible that the terms the group decided on were derived from their experience of the Memory Box Project and that they simply presumed that they would be expected to work in the same way. If this was the case, it sheds light on why the group did not keep to the contract terms. Even though the researcher did not suggest the terms of the contract, the group may have seen these as being the conditions of their "employment" or "contract" with the researcher and therefore, when they realised they were not going to be paid, the motivation for keeping the terms fell away. They may also have lacked the skills to take on difficult tasks such as discussing the problems they were experiencing with the research process (e.g. lack of payment) with the researcher as suggested by Nx.

The above discussion draws attention to two problem areas. Firstly, there is once again evidence that the group members lacked the confidence and the skills to fully participate in the contracting process. This again highlights the need for particular care in contracting with disempowered groups. Secondly, it appears that the participants lacked the skills and/or the motivation to follow through with the contract terms. This draws attention to the importance of reminding the group members of the contract and anticipating difficulties and/or lack of motivation in implementing the terms. It is also important that the group contract should be kept open for discussion, should

the group members discover that certain terms need to be added or changed, for the smooth functioning of the group. The idea of keeping the contract open was discussed in the group, but the contract was not referred to again in Participant Cycle 1.

3.4.2 Defining Roles (GRP1 and 2)

L: (Eng)	When you are coming here to ask us questions, when we answer you, what are you going to do with these answers?
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The above question arose right at the beginning of GRP1. It gives insight into the role the participants expected to take in the research study. They saw themselves as the subjects of the study and expected the researcher to take control of the process and decide on the direction of the research. The researcher was expected to ask the questions and also to decide on what should be done with the answers. It also shows that they saw the results of the research as belonging to the researcher. In this phase, the researcher attempted to challenge the participants to move from seeing themselves as passive subjects in the research to active participants with a role to play. Below is a short passage from GRP1, which demonstrates the way in which this task was approached.

Researcher (R): (Eng)	And then we also said: Who does research? (PAUSE while writing) We said: people from overseas. Okay so that's what we said. But we've already discovered that that is possibly not true! I'm not from overseas! I'm from here. (GROUP LAUGHTER)
L: (Eng)	Like you say you are from Cape Town, but you don't know Masiphumelele. So you are a visitor in Masiphumelele. (GROUP LAUGHTER)
L (Eng):	So it's the people from outside.
R (Eng):	Okay...so maybe the more correct answer is people from outside.
X:	SPEAKS IN XHOSA
Translator (T): (Eng):	X is asking if...can someone from here (X: (INTERRUPTS) from Masiphumelele), from Masiphumelele can do research?

The passage given above shows how the participants were challenged to question their own assumptions. The participants had assumed that the researcher was from overseas and were surprised to find out that she was from Cape Town. The researcher used this opportunity to start them thinking about who can be a researcher and this led to X's question: "Can someone from Masiphumelele....do research?" It seems that the participants had assumed that there was something preventing them from being researchers. This idea was not explored, but could possibly indicate a lack of self-belief and self-efficacy (that is, the participants might not have thought themselves able to do research).

The researcher responded to this by firstly, challenging the assumption and then by telling them that she believed in their ability. Later in GRP1, the researcher explained to the group that she was not the expert in the research, but that they were all equals in the process. They were told

that they all had knowledge and skills and that they, not the researcher, were the experts on their own lives. However, just talking about this issue was not sufficient to empower the participants to take up the role of co-researchers in the study. They continued throughout the research to take the role of subjects and to expect the researcher to direct the process and make the decisions. It is important to note, however, that the fact that the participants were asking questions, shows that they were willing to participate and benefit from the process, though they were not yet ready to take on the new role of co-researcher.

3.4.3 Addressing Expectations

The group expected to receive benefit from their participation in the study. In exchange for the answers they gave, they expected to receive some sort of help or assistance for themselves and their community. The kind of assistance that they expected was different for different group members:

Nx: (Eng)	I think research is something that can help people. Maybe they are suffering from sickness or maybe the others are not working.
L: (Eng)	Me, I want you to take these answers... like, there are many tourists at the University of Cape Town. So if people want to know about this research so you must bring this tape cassette....to the tourists....and they [are] going to come to sponsor...
Nx: (Eng)	But on my side, it's not about money, just for the advices and the support. I need a lot of support, because I know what I need. I am not talking about money... I am needing your advice just supporting me to make me strong...

L's comment shows a more passive expectation than Nx's. Both, however, were expecting something to be given from outside their community in response to their need. The implication was that they did not have the resources or the expertise to confront their own needs and that they were dependant on help from outside the community. They appeared to see the research process as a way of accessing that help - like a voice to the outside world or a platform on which to make their needs known. Nx's comment shows that she saw the researcher as an expert who could come along-side her to help her with her problems. (The group's expectation of payment is not covered in this section as it has already been described).

An important principle of the PAR process is that the solutions should come from the participants themselves and not from the outsiders (Babbie and Mouton, 2001). It is not that the outsiders and outside resources have no role to play, but it is that the initiative should come from the participants and not from outside. However, it is a natural process for the participants to expect the solutions to come from the outsiders involved in the process. This is a symptom of their disempowerment and indicative of low self-efficacy. It was important for the PAR process that these expectations should be addressed and that the researcher should make sure the participants understood that she was not promising money or answers to their problems. The researcher, therefore, explained this a number of times in the group sessions. The researcher

also aimed to strengthen the participants' self-belief and help them recognise their own ability to problem solve, through the PAR process. However, comments made by the participants later in the process show that the participants continued to expect the researcher to take the initiative in providing solutions to their problems (see Section 3.6). The problem of addressing participant expectations is further discussed in the next chapter.

3.4.4 Building Trust and "Safe Space"

It was important for the process that the participants should feel comfortable to share their personal needs and problems. The researcher's role in helping them to feel safe was to facilitate the building of trust both between herself and the participants and among the participants themselves. This was done by firstly, contracting for confidentiality (see Section 2.9.4 on page 30) and secondly, by the way in which the researcher responded to the participants in the group, particularly when they shared information of a sensitive nature. The way in which the participants responded to each other also affected the process. Below, examples have been given of verbal and non-verbal behaviour that either helped to build trust or had a negative impact on the process.

Positive Factors for Building "Safe Space"

- The researcher showed interest in what the participants were sharing by looking at the speaker, nodding her head and saying things like "yes", "mm" etc.
- When participants shared painful memories the researcher responded with sympathetic responses and facial expressions.
- The researcher thanked the participants for sharing with her and acknowledged the fact that they had shared painful memories.
- The participants frequently responded to each other's comments by saying that they had had similar experiences.

Negative Factors for Building "Safe Space"

- On a few occasions the participants and/or the translator laughed at something one of the group members had said. (Sometimes the laughter appeared a positive factor in the group as it seemed to help the participants relax and feel more comfortable, but on other occasions it appeared judgemental). The researcher intervened after the first group by speaking to the translator about laughing at the participants' comments (see Appendix M on page 134 for examples of judgemental laughter).
- The researcher did not always give the participants much time to talk about their experiences and she did not often ask them about their feelings. Instead, out of nervousness, she tended to hurry on to the next question.

3.4.5 Impact on the Empowerment Process

In this phase a number of key processes, for the empowerment process were begun. In the steps: "Defining Roles" and "Addressing Expectations", the researcher set out to challenge the participants to become active participants and co-researchers in the study. The group members were encouraged to believe that people from Masiphumelele can do research and that they have knowledge and skills to add to the process. While their expectations were being explored, it also became evident that the participants were looking to the researcher to direct the process and provide solutions to the issues under discussion. These expectations were challenged and the participants were encouraged to consider the possibility that they could be part of finding their own solutions. Just talking about this issue was obviously not sufficient to help them overcome feelings of inadequacy and powerlessness. However it was hoped that by making the suggestion and showing the participants that the researcher believed in their ability, this process would open the door to their starting to believe that they could become what was suggested. It was hoped that this would improve their sense of self-efficacy and self-esteem and thus prepare them for more active involvement.

PAR theory emphasises the importance of active participation in the research as a method of facilitating empowerment (Babbie and Mouton, 2001; Schurink, 2002). Thus, it is important that the participants are encouraged to be actively involved in all phases of the research process as through this process they can gain confidence, learn new skills and be empowered to participate more actively as the research progresses. In this phase, an opportunity was given for the participants to take part in the contracting process; however, the participants lacked the skills to take full advantage of this. Given their lack of empowerment, they needed more than just to be given the opportunity to contribute, they also needed to be guided in how they could contribute effectively to the process. Greater participation could have led to increased self-efficacy and more of a sense of ownership of the research and this might have increased their motivation to remain involved in the process.

3.5 Investigation Phase

In order to act appropriately in any situation, it is necessary to understand thoroughly the circumstances and the options available. The investigation phase was intended to provide the information required to devise a suitable action plan aimed at meeting one or more of the participants' needs. The phase contained two steps:

- Describing the situation
- Analysing the situation.

In the first step, information was gathered about the participants' circumstances. The aim of the process was to build a picture of the participants' lives from their descriptions. The second step involved making sense of the data generated in the previous step. Unfortunately, the participants

decided to withdraw, at the beginning of this step. Below these steps are described and the impact which each had on the empowerment process is explored.

3.5.1 Describing the Situation (“Look”)

The main focus of this phase was data generation. This was the phase in which the participants had the greatest level of participation. The participants did not direct the inquiry themselves. Instead they responded to the questions the researcher asked. The questions were fairly general and non-specific, however, and therefore the participants were able to direct the discussion to issues of importance to them (see Appendix E on page 109). The discussion highlighted the participants' circumstances and their needs. Their needs included: better living conditions, more income, and support from family and friends. They also had more abstract needs such as coming to terms with their HIV status and having hope for the future (see Appendix I on page 125). Stringer (1999) asserts that this step can have a liberating effect on the participants as, as a result of describing their circumstances and receiving feedback from others, they can gain new insights into their lives. Theorists have also written about the therapeutic value of group sharing in a supportive context (Bloch and Crouch, 1985). Below some examples of the therapeutic factors which occurred in the group, are described.

In the current study, the participants had the opportunity to discuss issues of importance to them, such as their experiences of discovering their HIV status, their experiences of rejection by family members and friends and their concerns for their children. Bloch and Crouch (1985) assert that it can be encouraging for group members to discover that other people have similar problems to themselves as this can help them to feel less isolated. The participants did not comment on whether they found the sharing in the group helpful. However, there were occasions in the group discussion where groups members said that they identified with what other members were sharing and added their own experiences (see Appendix K on page 129). In contrast to most of the rest of the group discussion, these comments were not given in response to a question from the researcher, but given spontaneously. It appears, therefore, that these comments were not made for the benefit of the researcher, but out of a need to identify with each other and thus experience a sense of togetherness. Some group members also shared some of their positive experiences and times in which they had overcome difficult circumstances (see Appendix K on page 129). Hearing about the successes of other people who are in similar circumstances to themselves may have been a positive factor for other group members and given them hope that they may also be able to overcome their difficulties (compare with Garvin, 1997). Listening to one another and giving each other support and acceptance was another positive therapeutic factor that occurred in the group (compare with Bloch and Crouch, 1985).

3.5.2 Analysing the Situation (“Think”)

This step involved making sense of the data generated in the previous step. It was anticipated that this would be a helpful experience for the participants as they could learn to understand the many facets of their reality better. Unfortunately, the participants withdrew from the study at the

beginning of this step and therefore did not analyse the data they had collected. However, they did make their own assessment of the situation, outside of the group context. Their assessment was that the project was interfering with their immediate need of income generation and was not providing them with sufficient benefits to motivate them to continue with it and, as a result, they decided to withdraw.

3.5.3 Impact of the Investigation Phase on the Empowerment Process

The positive aspects of this phase were the group interaction and encouragement and support gained from this. The participants were able to get a sense of not being alone from hearing other people's stories, and they were also able to receive encouragement, support and insight from each other. This was also the phase in which the most participation took place. In this phase, the participants were able to direct the group discussion to issues that were of concern to them and to participate in the process of supporting and encouraging each other. These factors are likely to have had a positive impact on the participants' self-esteem and thus on the intrapersonal aspect of empowerment. How much the participants gained from this is difficult to tell, however, as no feedback on these aspects was given. A negative aspect of this phase was the lack of opportunity for the participants to direct the inquiry themselves. The participants were thus not afforded much opportunity to take an active role in decision-making and problem solving.

3.6 Action Phase

This phase was meant to be the culmination of the work that had been done. The researcher had wanted the participants to develop an action plan based on the information that they had gathered and analysed. It was intended that through this process, the participants would solidify their newly gained perspectives and prove to themselves that they were capable of empowered action. Unfortunately this did not happen as the group members decided to withdraw from the process. The actual events of the action phase are described below.

In GRP4 and 5, the researcher explained that the next step in the process was for the group to choose a need and decide how to act on it. The participants reacted with reservation and uncertainty to this suggestion. They seemed to lack confidence in the group's ability to solve their problems. Some of the participants' responses are recorded below.

R: (Eng translated to Xhosa)	Okay, Nv?...What would you like to happen [next in the research]?
T: (translating for Nv)	She say she would also like you to solve their problems.

R: (Eng)	Do you think it [solving problems as a group] can work?
X: (Eng)	I think so, but I'm not sure...(LAUGHS). I can't say yes it can work, I can't say no...

Nv's response seems to indicate that she was still expecting the researcher to provide the solutions for the group. In contrast, X's reply shows a willingness to attempt to find solutions as a group, although he is unsure about the outcome of such efforts. It seems that the group started the process with an overconfidence in the researcher's ability to help them solve their problems. However, when the researcher made it clear that she did not have "the answers" for them and that she was expecting the solutions to come from the group, the group's confidence in gaining positive outcomes from the process appeared to drop. This may have played a role in the decision to withdraw. While the researcher was exploring the possibility of action with the group, the participants were, unbeknown to the researcher, forming their own "action plan" outside of our group discussion - that of withdrawal. X informed the researcher of this decision in GRP6, the last focus group in this cycle.

3.6.1 Impact of the Action Phase on the Empowerment Process

This phase is likely to have had a mainly negative effect on the empowerment process. The participants were unwilling or unable to confront the researcher over their disappointment regarding the payment issue and therefore the matter remained unresolved. This is likely to have been a source of frustration and disappointment to them. Their sense of self-efficacy may have been impacted by their inability to manage the conflict successfully and express their feelings appropriately. It is possible that they also felt guilty about "disappointing" the researcher and this may have affected their sense of self-esteem. The participants' behaviour in the situation showed a lack of empowerment and assertiveness skills and they were not given the opportunity to improve on these skills. Participant Cycle 1, thus ended on a low note.

3.7 Participant Cycle 2

Because of the participants' time constraints, Participant Cycle 2 was a much shorter cycle consisting of only 2 focus group sessions. In Participant Cycle 2, each of the phases was revisited in a slightly adapted form. The main component of the preparation phase had to do with re-negotiating entry and re-contracting. The investigation phase consisted of giving feedback to the participants and receiving some feedback from them. The final action phase involved discussing with the participants what they wanted to be done with findings. The sound quality of the tapes of GRP7 and 8 was poor and a lot of the participants words were lost (see Section 2.8.1 on page 26). Therefore only the key features of the cycle are described in this section. The improvements that the researcher attempted to introduce into Participant Cycle 2 as a result of reflection on the previous cycle are also given.

3.7.1 Preparation Phase

A major concern arising from what occurred in Participant Cycle 1 was whether the participants would be motivated to attend another session. The researcher therefore decided to hold a party as an incentive to encourage the participants to attend. This incentive was chosen, because the participants had frequently mentioned during Participant Cycle 1 that they were hungry. Nx had also said that they were unable to afford the good food that they required in order to keep themselves well and healthy (see Appendix I). At the time, the researcher had not responded to these hints as she did not want to encourage the participants to become reliant on her. However, in retrospect, the researcher feels that providing food at the meetings might have been a simple, yet inexpensive incentive to encourage attendance. (Issues around incentives will be discussed in the next chapter). This method appeared to work, as all but one of the participants, who had moved to Khayelitsha, attended GRP7. The other problem identified from Participant Cycle 1 was the lack of participation of the group members in the contracting phase. However, the researcher decided that there was not sufficient time to renegotiate these terms in detail and therefore kept to the original agreement. The researcher re-contracted with the participants by reminding them of key terms in the consent form and group contract made previously and checking whether these were acceptable to them.

3.7.2 Investigation Phase

Reflection on Participant Cycle 1 revealed three areas of concern in the investigation phase. The first concern was that the participants did not have much control of the process and the decision-making around the focus of the research and the methods used. The second concern was that, due to the interruption of the process, the participants had not been given the opportunity to benefit from reflection on and analysis of the information that they had gathered. The researcher was anxious to ensure that the process did not go to waste and that the data gathered would be of benefit to the participants. The third concern was the lack of feedback from the participants on what had gone wrong in Participant Cycle 1. Once again, it was decided that there was insufficient time to re-negotiate the process and give the participants more control over what happened and thus this phase was once again researcher-driven. The researcher analysed the Participant Cycle 1 data and three illustrations were developed in order to explain the feedback visually and creatively. These are described below.

- **The “life road” poster:** This was a picture of a winding road which represented the participants’ lives. Bends in the road were symbolic of major turning points in the lives of the participants and pictures were pasted on to the road to represent significant events and problems that had occurred in the participants’ lives (see Appendix B.1 on page 95)
- **The “shield” poster:** This was a picture of a person holding a shield. The shield was divided into four quadrants, which were labelled knowledge, attitudes, skills and resources. In each of the quadrants the researcher used words and symbols to represent the knowledge, attitudes, skills and resources that she felt the participants had demonstrated in the group (see Appendix B.2 on page 97).

- **The “cartoon summary”:** This was a summary of the events of Participant Cycle 1 done in cartoon format, which included the key events of each of the focus group sessions, including the participants’ withdrawal from the process and the researcher’s thoughts and feelings around this event (see Appendix B.3 on page 101).

The participants appeared to really appreciate the feedback that was given to them. The participants did not, however, get much time to participate in the feedback sessions, due to the researcher miscalculating the time required for the feedback and spending most of the sessions talking. The feedback the participants gave on these issues was also difficult to make out on the tape and therefore this can not be presented in much detail. The major themes covered in the feedback are outlined below:

Validation of the Strength, Courage and Positive Attitudes the Participants had shown In facing Difficulties In Their Lives

On the “life road” poster, the researcher pasted pictures symbolising this courage and strength. These included: a lion and a sunflower. The researcher also used the “shield” illustration to represent the participants’ bravery and resourcefulness in facing their problems. The purpose of this feedback was to encourage the participants by pointing out their positive qualities.

Acknowledgement of Their Sufferings and Grievs

Pictures were placed on the “life road” posters to represent some of the sufferings and losses the participants had experienced. These included: moving away from home, the loss of loved ones, the loss of possessions in shack fires and the diagnosis of HIV. The participants responded positively to this acknowledgement of their experiences and some of them commented on particular pictures, which stood out for them. Unfortunately most of this feedback is inaudible on the tape.

Explanation of Elisabeth Kübler-Ross’s stages of grieving

The researcher had noted that the participants’ descriptions of their response to their diagnosis with HIV followed many of the phases outlined by Kübler-Ross in her explanation of the grieving process (i.e. denial, anger, bargaining, depression and acceptance) (Kübler-Ross, 1969). Appendix C on page 105 gives a brief explanation of the stages of grieving and shows how the participants’ descriptions relate to each stage of grieving. The researcher decided to explain this to the participants in order to validate their experience and reveal to them that the confused emotions that they had experienced were a normal human response to grieving and not a sign of weakness or abnormality. The participants seemed to understand and identify with this explanation. The expressions on their faces showed comprehension and recognition of their own experiences in the explanation of the stages and both X and Nx commented on how they felt the stages of grieving related to their experience. These remarks were, unfortunately, inaudible on the tape.

Knowledge, Attitudes, Skills and Resources

The researcher used the “shield” poster as an illustration of how the participants had used their knowledge, attitudes, skills and resources in the past to “shield” themselves from the negative impacts of HIV. The researcher explained to the participants that they have knowledge of HIV/AIDS and themselves; positive and hopeful attitudes to life; new skills such as writing about their feelings; and resources such as the memory boxes and the support group. She further explained that she had observed, through the process of working with them, that they were using these attitudes, knowledge, skills and resources to protect themselves and help them overcome difficult circumstances. She commented that their attitudes were not always positive and hopeful and sometimes their “shields” were stronger and sometimes they were weaker. Paper was given to the participants and they were encouraged to make their own “shields” and to reflect on how their “shields” could be used in the future to better protect themselves. (There was not time to do this in the focus group sessions, however).

Reflection on and Evaluation of the Research Process

The researcher used the “cartoon summary” of the group process to remind the participants about what had happened in Participant Cycle 1 and to stimulate discussion around this. The last few frames of the cartoon showed the researcher's disappointment and confusion about what had gone wrong. The researcher was hoping for feedback from the participants on what they perceived to be the strengths and weaknesses of the research process, as well as on the reasons for their withdrawal. Unfortunately, most of the participants' comments, with an exception of Nx's, were inaudible on the tape. Nx's feedback is given below.

Nx: (Eng)	I think the research is very good and we had a lot of mistakes. Sometimes we did not tell when there are times we are not coming.. [<i>the rest was inaudible</i>]
Nx: (Eng)	I think from last year there were researchers from UCT who gave us money, so I think that is our problem. We were thinking maybe you were going to give us money because we were not working.

The quotes given above show embarrassment and regret, at least on the part of Nx, concerning the way the group members responded to the misunderstandings. Unfortunately there was not much time for reflection and comments on the process and the participants seemed to be too embarrassed to comment on what they experienced as negative aspects of the research. Thus, while it was helpful for the researcher to hear Nx's comments, more could have been gained from this process. Further discussion around how the conflict had been handled and how it could have been managed better, could have been an opportunity for the participants to learn conflict management skills and for the researcher to understand better what her mistakes were.

3.7.3 Action Phase

Three actions were decided upon in this cycle:

- The researcher offered to write an article about the research and attempt to have it published in a magazine that could be read by other people living with HIV/AIDS. The participants agreed to this and the researcher plans to do this once this dissertation is completed.
- Nx suggested that she and X could pass on the knowledge that they had gained to other people in the community through their new jobs (Nx and X have been given posts in the local clinic working as translators for an HIV/AIDS counselling project).
- Nx also wanted the group members to go back to the support group from which they had been recruited into the Memory Box Project and report on their experiences and how much they had gained from being involved in the Memory Box Project. This action mainly relates to the Memory Box Project and not the current study, but it is recorded here as it shows the participants' eagerness to pass on the knowledge and skills that they have gained. The researcher contacted the Memory Box coordinator about this suggestion and it was agreed that she would arrange this for the participants.

3.7.4 Impact of Participant Cycle 2 on the Empowerment Process

As described above, the researcher introduced a few changes to Participant Cycle 2 based on reflections on the previous cycle, with the aim of improving the effectiveness of the cycle and adapting it to suit the participants' needs. These changes and their impact on empowerment are described below:

- The cycle was shortened in order to fit in with the participants' time constraints. This change was helpful in that it made it easier for the participants to take part and thus gave them the opportunity to benefit from the process, but it obviously limited the time available for empowerment to take place.
- An incentive was used at the beginning of the cycle to attract the participants to the group. This change was helpful for encouraging participation and therefore giving the participants the opportunity to benefit from the process.
- Feedback was given to the participants about the information that they had shared in Participant Cycle 1. The participants appeared to appreciate this. However, it is difficult to assess how much this impacted the empowerment process, because of the lack of feedback from the participants and the poor sound quality of the tapes, which made it difficult to hear the comments they made.
- The participants were given an opportunity to reflect on the feedback and on the research process and make comments on how it had impacted on them (the time for reflection was, however, very short). In retrospect, it seems that less feedback and more time for reflection on the part of the participants would have been more beneficial to the participants and more empowering for them.

- An opportunity was also missed in this phase to reflect on and learn from the problems that occurred in the research and for the participants to explore alternative methods of dealing with the conflict that had taken place.

3.8 Other factors Affecting the Empowerment Process

The above discussion has highlighted some of the key factors that played a role in influencing the research process and impacted on participant empowerment. There are, however, a number of influential factors that have not yet been explored. Below these are highlighted briefly and their impact is considered.

3.8.1 Participant Withdrawal from the Research

The participants started out being enthusiastic about taking part in the study, and then this eagerness waned when they realised that they would not be paid for their time. It would be a mistake, however, to conclude that there were no other factors involved. In fact there appears to be evidence in the transcriptions supporting the idea that there were other factors involved in both their initial eagerness and in the waning of this enthusiasm. Below, the positive and negative factors impacting on their motivation are described and then the impact of their withdrawal on the empowerment process is considered.

Positive Factors Impacting on Motivation to Take Part In the Research

In GRP1, the participants made some comments that indicate that they expected benefits from being involved in the research process. Some of these benefits included: support and advice from the researcher, an opportunity to make their needs known to others, foreign sponsorship, an opportunity to learn new skills and a chance to help others. The participants also referred to wanting to be “strong” so that they could face the difficulties in their lives. The concept being “strong” was used by the participants to refer to both emotional and psychological strength to face life’s difficulties as well as physical strength to ward off opportunistic infections (see Appendix O on page 137). It seems logical to infer that this idea of being strong, at least in the emotional/ psychological sense, is similar to the concept of empowerment and thus logical to conclude that the participants were motivated to be empowered. Nx appeared particularly motivated to find ways to become “stronger” and she seemed to think that the research process could help her in this regard. However, as mentioned above, this motivation was not sufficient to sustain the participants’ involvement in the project.

Negative Factors Impacting on Motivation to Take Part In the Research

Disappointment over the payment issue, was named by Nx as the main reason the participants withdrew. However, there may have been some other factors involved as well. Loss of motivation

may have occurred as a result of the participants starting to think that some of the other benefits (e.g. support and advice, sponsorship etc.) they thought they would receive, would not be forthcoming. A further reason for withdrawal is implied by the stage at which the participants withdrew - the action stage. The participants chose to withdraw just at the point when the group were supposed to be discussing action. The group members had expressed scepticism about their ability to solve their own problems (see Section 3.6) and this may also have been a factor in motivating their withdrawal.

Impact on the Empowerment Process

The most obvious effect of the participants' decision to withdraw, was that they missed out on possible opportunities to gain new skills and awarenesses in the PAR process and thus experience empowerment. However, a more positive impact may also result. The misunderstanding over payment and the participants' disappointment may result in the participants being more cautious over contracting in the future. It is hoped that they will make more effort to spell out the terms of future contracts and ensure that these are to their liking.

3.8.2 The Language Barrier

In this research, a translator was employed to translate from English to Xhosa and from Xhosa to English during the focus groups. The language barrier and the translation process had a number of effects on the group process. These are described below:

The Language Barrier had an Effect on Participation

Although all the conversation in English was supposed to be translated into Xhosa, in practice this did not always happen for the following reasons:

- There were times when the participants indicated that they did not need translation or said that they would ask if they did not understand. This worked well for those who were more fluent in English, but some of the others, particularly Nt, became lost at times and they did not always stop the group to ask for translation.
- There were times when the researcher forgot to pause regularly to allow translation be done and thus some sections of English dialogue were not fully translated into Xhosa as the translator could not remember the whole conversation and thus only translated the end of it.
- Sometimes translation was forgotten about as the researcher and translator became absorbed in the discussion.

The above-mentioned problems with the translation process meant that some of the participants whose English was less fluent, struggled at times to follow the group discussion and this meant that they were less likely to contribute to the discussion.

The Translation Process Discouraged Spontaneous Discussion and Interaction

The translation process tended to inhibit spontaneous discussion and interaction between the participants. Interaction between participants is very important in PAR as the group members need to be able to interact with each other in order to discuss issues and make decisions. The researcher attempted to solve this problem by encouraging the group members to speak in Xhosa to one another and then asking the translator to summarise the discussion at suitable intervals. This strategy worked for short periods of time in GRP2 and 3, but would have worked more effectively if this discussion had been facilitated in Xhosa, as without the intervention of a facilitator, the conversation tended to peter out.

Problems In Communication and Misunderstandings

The researcher's ability to convey important information to the group members and to understand and respond to their comments and questions, was inhibited by her inability to speak Xhosa and some mistakes made by the translator (see 2.8.1 on page 26). The language barrier probably also played a role in the misunderstanding over payment and there may well have been other more minor misunderstandings that went undetected. The researcher was also unused to working with a translator and made many mistakes in the process of learning how to do this. These include: not pausing at frequent intervals for translation to take place and using complex terms and concepts, which were difficult to translate. However, both researcher and translator appeared to improve as the research progressed. Evidence of this was given by Nt who commented after GRP3 that she was following much better than in the beginning. The transcriptions also show fewer long passages of speech without breaks for translation and fewer occasions in which speakers had to keep repeating themselves. Before the beginning of Participant Cycle 2, the researcher tried a new strategy to improve the translation process; she spent some time with the translator prior to the research session and explained some of the concepts she wanted to convey to the group. This appeared to help the translation process considerably.

3.8.3 Facilitation

Koch and Kralik (2001) assert that the facilitator plays an important role in PAR and has an impact on group dynamics and a major influence on the outcomes of the research. For this reason they recommend that expert facilitators be used (Koch and Kralik, 2001). This was not possible in this study, due to the lack of funding. The researcher had had only a limited amount of experience as a facilitator and had never done PAR before. Below the researcher's strengths and weaknesses as a facilitator are explored and comment is made on the impact this had on the empowerment process.

Strengths

- The researcher used her listening skills (both verbal and non-verbal) to show the participants that she was listening and that she sympathised with them and appreciated their contributions (see Section 3.4.4 on page 40)
- The researcher reflected on the process and learnt from past mistakes. For example, in the beginning of the process the researcher tended to forget to stop to allow for translation and to make sure the group were following. The researcher worked on this problem and in later group sessions this improved.
- Extensive feedback was given to the participants on Participant Cycle 1 in GRP7 and 8 (see 3.7.2 on page 45)

Weaknesses

- Mistakes made in working with the translator (see Section 3.8.2 on page 50)
- Discomfort with silences and, as a result, talking to fill the gap
- Being too directive in the process and not allowing the group to take control
- Using closed or leading questions
- Not reflecting on group processes and confronting underlying conflict, for example, the misunderstandings that led to the group's withdrawal
- Missing opportunities to facilitate the learning of new skills

Effect on the Empowerment Process

It appears that the researcher's overly directive approach inhibited the empowerment process as it deterred the participants from taking more control over the research. The researcher's lack of experience in reflecting on group process and confronting conflict may also have impacted on group cohesion and ability to deal with problems constructively. As previously mentioned, the opportunities created by the conflict and misunderstanding could have been used to help the participants develop conflict management skills. On the positive side, however, is the fact that the researcher managed to re-negotiate entry with the group and use the information she had gathered to encourage the participants.

3.8.4 Group Dynamics

Group dynamics refers to the study of the behaviour of people in groups and their interaction with one another (Johnson and Johnson, 1997). In a research process that involves a high degree of group interaction, such as PAR, group dynamics play an important role. It is not, however, possible to explore all the aspects of group dynamics that occurred in this study. Therefore only a few of the main aspects have been chosen. These are discussed below.

Diversity and Conflict

Johnson and Johnson (1997) point out that diversity within groups can be helpful as the different perspectives of different members can add to the creativity of the group and the richness of the discussion. However, differences between members may result in conflict, which if not handled constructively, can inhibit the functioning of the group (Johnson and Johnson, 1997). Although the group in this study was composed of people from similar socio-economic backgrounds, culture and language, there were some marked differences between the group members in a number of areas. These include: age, gender, family situation and personality as well as some notable differences in their experience of HIV and their response to it. There were also some quite notable differences between the values, interests and needs of the different group members. One would not expect a 20 year old woman with no children to think the same way as a 40 year old mother of three, or a 29 year old man. These differences in needs and interests appeared to impact on the group's cohesiveness and identity as a group. In GRP2, when the group first began discussing their needs, the group members asked if they could answer one by one, as they felt that their needs were very different. Later in the process, however, the group members were able to discuss issues more spontaneously as they identified with the problems that other group members raised (see Appendix L on page 132).

Johnson and Johnson (1997) point out that prejudice and discrimination can act as barriers to effective group functioning in diverse groups. In GRP2 Nx made the following comment:

Nx: (Eng)	The time I got the results that I am HIV positive, I took the decision not to have a boyfriend again till now from 2001 till now. I just stay with my children. And when I see a man even just walking around in the road I hate him and I don't know why...
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X, the only man, did not make any response to Nx's statement and this issue was not further explored, but it is likely that this comment alienated X and made his situation as the only man in the group, more uncomfortable. X was also a relatively new member of the group as he had joined the group only a month before the current study started and after the others had been together for two months. No other indication of conflict between X and the rest of the group was given. However, the group tended not to talk about their feelings towards one another or the group process and therefore this does not necessarily mean that there was not further underlying tension.

Active and Passive Members

Smithson (2000) points out that there is often one or more group members in focus group research who tend to dominate the discussion. As a result the opinions of others who are less dominant may not be heard. In the current study, Nx was noticeably the most dominant speaker, followed by X and L; Nt and Nv were the quietest members of the group. (Appendix N shows the difference in the amount of participation by each speaker in each of the focus groups.) At times Nx's dominance of the group discussion kept quieter group members out of the conversation

and thus negatively affected participation. However, Nx's energy, enthusiasm and contribution of ideas was also helpful to the group process. It is noticeable in GRP3, that the other group members participated more than in the first two groups. This may have been because they had gained more confidence and were feeling more comfortable and/or because more of the discussion was conducted in Xhosa.

Communication

Johnson and Johnson (1997) point out that effective communication is vital to any group's functioning. In PAR, the participants are meant to interact with one another, discuss ideas and learn from each other (Stringer, 1999). In the beginning part of this study, group members spoke mostly to the researcher and not to each other, but this started to change in GRP3, where there was a long passage of dialogue in which the participants spoke mostly to each other (see Appendix L on page 132). This was around topics of common interest. However, once the topic was exhausted, the conversation went back to the stilted process of the participants answering the questions one by one. The communication process was also inhibited by the language barrier, as translation tended to interrupt the flow of conversation. The researcher also tended to talk too much out of nervousness and not give the participants enough opportunity to contribute to the discussion.

Developing trusting relationships between group members is also important for facilitating open and honest communication. Power imbalances can inhibit the development of these relationships and make communication more difficult (Bryan et al., 2002). In this study, the researcher attempted to establish equitable relationships within the group by assuring the members of her respect for their knowledge and skills. She also attempted to form a "safe space" in the group in order to facilitate the sharing of personal information and experiences (see 3.4.4 on page 40). The participants shared quite a lot of personal and painful information in the group, thereby showing that they felt safe in the group. However, they were not able to challenge the researcher over the misunderstanding that occurred over payment. Previously, it has been suggested that this was due to the participants' lack of empowerment. It seems likely, however, that the nature of the relationship between the participants and the researcher may also have played a role. A more democratic and trusting relationship might have enabled the participants to raise this issue. The problem of how to establish more equitable relationships with the participants is discussed in the next chapter.

Decision-making

The participants were not given much opportunity to take part in the decision-making process as the researcher tended to be too dominant in her interaction with the group. However, some opportunities for group decision-making arose in the contracting process. The decision-making process was conducted in Xhosa in the group and only the outcome of these interactions was recorded on the transcriptions as the Xhosa discussion was difficult to make out on the tape. It is, therefore, not possible to evaluate how this process was conducted. However, listening to the

tapes revealed that Nx was the dominant speaker in these interactions, with some contributions from L and X. This indicates that the process was not democratic, but strongly influenced by Nx. The language barrier prevented the researcher from facilitating the decision-making process and assisting the participants to reach consensus, rather than going with the ideas of the most dominant group members.

Impact on the Empowerment Process

The above discussion highlights some important aspects of the group dynamics in this research. These include:

- Differences in the values, interests and needs of the group members;
- A possible underlying tension between the one male member and the four female members;
- The dominance of Nx and the lack of participation from Nv and Nt, which may have also resulted in undemocratic decisions being made.
- A lack of interaction and communication between group members, with the participants tending to talk to the researcher rather than to each other.

These factors had an impact on the group's cohesiveness and ability to function as a team towards achieving the goals of the research. The impact of these factors on the process could have been lessened by more skillful facilitation.

3.8.5 The Link with the Memory Box Project

Linking with the Memory Box Project had a number of consequences for the research study, some of which were quite positive and others negative. On the negative side, the participants assumed that the project would operate in the same fashion as other UCT projects and this is how the misunderstanding over payment arose. They also appeared to make other assumptions around the role that the researcher would take in the study, which could have been related to their misunderstanding of the relationship between the study and the Memory Box Training Project. These include: assuming that the researcher would take a directive role in the research and expecting the researcher to provide solutions to problems. Another negative aspect was related to the fact that the researcher did not take part in the selection of the participants. As a result, the researcher had not had the opportunity to build a relationship with each participant before the study started and thus have some idea of the participants' strengths and weaknesses and what the composition of the group would be like. Having this background knowledge could have helped the researcher to structure the study more effectively to suit the needs of the group.

Some of the positive aspects of the link with the Memory Box Training, have been outlined in Section 2.5.1 on page 15. Other positive aspects of this link relate to the empowering nature of

the Memory Box training, which appeared to enable the participants to participate more actively in the research process. For example, the Memory Box training introduced the participants to the skills of reflecting on and talking about their thoughts, feelings and experiences. It also gave them an opportunity to give feedback to each other and participate in encouraging and supporting one another. All of the participants reported that the memory box work was extremely helpful to them as people living with HIV. Some of the participants commented that it was helpful for them to be able to write about their difficult experiences and this helped them to express their emotions and reduce their stress levels. Some of the participants comments on the Memory Box training are given below:

Nx: (Eng)	I think it's very important to the people who are HIV because the people they didn't have a person to share some things. But if you do the... memory..box it's easy because you write down all your problems and the stress goes away...
T (translating for Nt):	Nt is saying that the memory box is good for her, because she is not thinking about anything, she is writing everything down.

3.8.6 Hope and Despair

In their descriptions of their lives, the participants appeared to be motivated to change their circumstances for the better. In spite of their strong motivation and courage, however, there were times in which the participants voiced a sense of frustration and despair at the seemingly overwhelming problems with which they were faced. This frustration and despair was tempered by moments of hopefulness and even triumph as they recounted circumstances in which they had overcome great difficulties in the past and this gave them hope for the future. Some extracts from the transcriptions are given below to illustrate these contrasting descriptions of hope and despair (see Appendix D on page 107 for more examples).

Despair

R:	What changes have come about in your life since finding out about the HIV?
T (translating for Nt)	Nt said that there is nothing that makes her happy. Everything changed, because she knows that any day she can die.

Nt: (Xhosa)	That day [day of diagnosis with HIV] was different. It was like I was in another place. On that day it was not the same as the other days, and the sun seems dark, everything was funny everything was also different.... Everything changed, the world changed, just everything changed.
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(Nt's quotes given above refer to how she felt at the time of her diagnosis. It is not clear whether she still felt the same way at the time of the research, but is likely that she may well have done, seeing that she had just lost her baby and was struggling with illness herself.)

X: (Xhosa)	To stay without a job, because I am not working anymore that makes me sad. I don't want to sit doing nothing, because I'm going to steal from the others(LAUGHTER) and then I'm going to jail if I rob the others ..Staying without a job is something that makes me sad. Also think about every day... think about why I can't get a job.
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Hope

Nx: (Eng)	Me..last month, in May I was very sick.. very sick and come to see this doctor....and my CD4* [count] it was 147.... And the doctor told me they are going to start with the treatment....but the time I came back to them again.. my CD4 ..my CD4 now is 420 ...so they cancelled that treatment. So I'm always hoping that may be I'm going to be alive till the government get a cure for us....
R: (Eng)	So you have hope?
Nx: (Eng)	Yes I have hope always. Because I was worried that time my CD4 was 147 and I was very very weak and I was worried, because I think maybe I'm going to be sick, but now I feel very strong and healthy...very strong!

CD4*¹

These contrasting feelings of hope and despair reported by the participants are likely to have had implications for the research and empowerment process. Feelings of despair and hopelessness may have negatively impacted on the group members' willingness to participate in group activities. It may also have impacted on how the group members felt about the prospect of engaging in action aimed at meeting their own needs. Alternatively, the times of feeling hopeful and triumphant, may have given some group members' energy and enthusiasm to participate. In one of the quotes given above, Nx spoke about recovering from pneumonia and how this made her feel strong and hopeful again. This story seemed to be encouraging for the whole group and Nx's positivity may have helped the others to be more optimistic.

3.9 Conclusion

In this chapter, the research process has been explored in detail to uncover its impact on empowerment. This analysis has described both the strengths and weaknesses in the way the

¹ The CD4 count refers to the number of CD4+ T-lymphocyte cells per micro-litre of blood. The HIV virus attacks these cells and reduces the CD4 count, thus depleting the immune system and leaving the patient vulnerable to opportunistic infections. Once the count has gone below 200, it is considered to have reached a critical level and anti-retro-viral therapy is often initiated if available (Lachman, 1999; American Association for Clinical Chemistry, 2005).

methodology was implemented and a number of other factors impacting empowerment. From this discussion, a number of challenges emerge which relate not only to this research, but also could be potential problem areas or challenges for future PAR studies. These include:

- Problems related to engaging participants to take part in PAR and maintaining involvement;
- Power imbalances and the issue of participant control over the process;
- Problems relating to group facilitation and conflict management;
- Problems related to crossing language and cultural barriers.

In the following chapter these problem areas are explored further and compared with the problems encountered by other studies, which are examined for insight into how these challenges can be addressed.

Chapter 4

Discussion

4.1 Introduction

In this chapter, the discussion focuses on exploring other research which encountered similar challenges to those experienced in the current study. These other studies are examined for insight into these challenges and alternative ways of dealing with them. The discussion centres around five main issues. These are: engaging people to participate in PAR; achieving participant control of PAR; facilitating the group process; and crossing language and cultural barriers.

4.2 Engaging People to Participate in PAR

Participation has been closely linked with empowerment. Research suggests that participation provides a key opportunity for individuals to obtain the skills, knowledge and critical awareness vital for empowerment. It is therefore important to understand why people choose to participate and what hinders or promotes this participation (Prestby et al., 1990). Prestby et al. (1990) propose that in general people decide whether or not to participate on the basis of a cost-benefit analysis. In other words, they weigh up the amount of benefit they perceive that they will gain from taking part and balance it against the potential cost of involvement. Cornwall and Jewkes (1995) point out, however, that people's motivation to take part tends to fluctuate over time. Participants may enter the research process with a preconceived idea of what benefits they are likely to gain from the research. Their enthusiasm, therefore, is likely to dwindle, if they discover that they are not going to receive these benefits (Cornwall and Jewkes, 1995). This is in fact what happened in the current study - the participants withdrew after discovering that their expectation of payment was not going to be fulfilled. The above discussion raises two important issues in relation to this study and to PAR projects in general. The first is how participants can be persuaded to become involved and remain involved; and the second is the problem of addressing their expectations. These issues are explored below.

4.2.1 Encouraging Participation

Prestby et al. (1990) found that the use of incentives and “cost management” strategies, as employed by voluntary organisations, led to members having increased perceptions of the benefits of involvement and lower perceptions of the costs. Thus Prestby et al. (1990) suggest that these strategies can be used to promote participation in voluntary organisations and other projects. Incentives used by the organisations in this study included: gifts, discounts on food, hosting money-making events, skills training, hosting social events, making people feel welcome, giving praise and recognition at meetings etc. “Cost management” efforts included keeping meetings short, arranging meetings at convenient times, providing child care, rotating duties amongst members, giving opportunity for people to express their views etc. Based on their study results, Prestby et al. (1990) further suggest that people are most motivated to participate when they are offered a variety of benefits that they perceive to be valuable and there are few costs involved. In other words, there needs to be a correspondence between the benefits offered and what the individual perceives to be valuable. Adamsen et al. (2001) found that the men in their study were attracted to participate in support groups for cancer patients, by the possibility of gaining information and improving physical strength (the groups involved exercise classes). This finding shows a contrast between the benefits which were found to attract men and those which have been found in other research to attract women to support groups. For women, intimacy and emotional support are important benefits (Adamsen et al., 1992 as cited by Adamsen et al., 2001).

These findings offer insight into what occurred in this research study, as well as giving insight into how future studies can encourage people to participate. In this study, the withdrawal of the participants indicates that they were not satisfied with the benefits offered to them. Although it appears that they were attracted by the opportunity to gain knowledge and learn skills, this was not sufficient to motivate them to stay involved unless they were going to be paid as well. Rifkin (1990, as cited by Cornwall and Jewkes, 1995) observes that the poor are often too busy securing the basic necessities of life to be able to afford the time and the energy to put into other activities. This appears to have been the reality for the people in this study; thus the benefits offered were not effective as they did not fit the needs of the participants at the time. Unfortunately, it was not possible to offer payment to the participants as the researcher did not have a grant to support the study. However, other incentives or cost management strategies could have been used. Possible alternative strategies include: making the meetings less frequent and/or changing the time or making it more flexible; providing low cost food at the meetings; and starting the PAR process with action aimed at income-generation. It is not possible to tell whether these strategies would have been effective. However, from what is known of the situation, it seems that these incentives offer a better fit with the participants' needs than what was offered in the study.

Cost management and incentive management strategies are, however, dependant on the researcher being aware of the needs and desires of the people involved so that he/she can adapt the project to suit the participants. In this case, the researcher was not aware until it was too late what the real problem was. This raises another important issue, that of addressing unspoken

expectations. This topic is discussed below along with other aspects to do with addressing expectations.

4.2.2 Addressing Participant Expectations

Another important factor to be considered is the expectations with which the participants enter the process. These expectations can arise, as they did in this study, without the researcher making any suggestion that these benefits might be available. The expectation of payment arose, because the participants misunderstood the relationship between the UCT Memory Box Project and the researcher's study. The researcher entered the research site under the auspices of the UCT Memory Box Project and thus her study was assumed to also be a UCT project. Low et al. (2000) also experienced complications as a result of the participants misunderstanding the researchers' relationship to a partner organisation - the social services agency which funded the project. The participants assumed that the researchers were working for the social services agency and therefore would have the same goals and interests as this organisation rather than sharing the interests of the participants. Unlike the current study, this misunderstanding did not have serious consequences for the Low et al. (2000) study. However, the experience of Low et al. (2000) as well as the current study, serves to underline the need for researchers to be explicit about their relationships with other role-players and to anticipate misunderstandings in this regard.

In this study, the participants did not voice their expectation of payment, either at the beginning of the process when the terms of the contract were negotiated, or at the point when they discovered they were not going to be paid. This appears to indicate that they lacked the skills and/or the confidence to do so. Thus it seems that in order to address this problem, it is important that unspoken expectations are anticipated and that the contracting process caters for some way of dealing with this issue.

It is not unusual that the prospect of a research study starting in a poor community, should evoke expectations of benefit on the part of the community members. Community members in the Brugge and Kole (2003) study, defined a successful research study as one that brought about benefit and improvement to the community. They felt that it should bring knowledge, resources and skills to the community. It is, in fact, important that the participants should perceive there to be benefits for them from taking part, in order to encourage them to get involved. However, as pointed out by Cornwall and Jewkes (1995), the researcher needs to be careful not to raise unrealistic expectations that cannot be fulfilled in the process of motivating the participants to take part. It is also important, as shown by this study, that the researcher is aware of the expectations the participants hold and negotiates with them around what is realistic in the context of the time and budget available to the project.

The participants held expectations of receiving a number of different kinds of benefits. L spoke about the research leading to foreign sponsorship, but Nx said she was more interested in support and advice (see Section 3.4.3 on page 39). The participants also said on a number of occasions that they were hungry. These comments were interpreted as being hints that they would like food to be provided at the meetings. These expectations did not match up with the

goals that the researcher held for the project; that is, that the group should work together to solve a particular problem of their choice, rather than the researcher providing expert solutions or resources. The researcher did not negotiate with the participants around these conflicting expectations. Instead she disregarded the group's expectations in favour of her own. The participants were only asked whether they agreed or not and they were not encouraged to express doubts or reservations. Initially they agreed to what the researcher suggested and only much later, when particularly pressed to give their opinions, did they express doubts about the viability of these ideas. It is possible that their non-attendance and withdrawal from the group was their way of expressing their disagreement and dissatisfaction with the project's focus and agenda. Perhaps they felt that their ideas had been overlooked and therefore did not feel that the research was going to meet their needs.

Low et al. (2000) also found that there was a discrepancy between their ideas of what the focus of the research should be and that of the participants. The researchers wanted the study to focus on social action, while the participants wanted the group meetings to satisfy their needs for support and connection with others and were not that interested in social action. Simonson and Bushaw (1993) experienced a discrepancy in what the researchers thought the community needed and what the community members thought was needed. This discrepancy led to conflict and the community members resisting the researchers' efforts. Gray et al. (2000) also experienced conflict between their agenda and that of the participants in their study. In dealing with this issue, they emphasised the importance of flexibility on the part of the researcher and a willingness to accommodate the needs and desires of the participants, even if these run contrary to the researcher's ideals.

As explained, the researcher did not have the funding to pay the participants. The researcher could have provided food at the meetings, but did not do so initially as this seemed contrary to the project's goals of creating independence. However, it appears that without these incentives the participants were unmotivated to take part. This raises the question of whether it would be appropriate to provide these kinds of incentives to initiate participation, even though they appear contrary to the principles of PAR. In retrospect, the researcher feels that it is necessary to take into account the realities of the participants' situation. It seems that while people are faced with the daily struggle of survival, they are unlikely to take part in something that takes up their time, but does not offer immediate relief to their most pressing needs.

4.3 Achieving Participant Control of the PAR Process: A Question of Power

Cornwall and Jewkes (1995) suggest that the key difference between Participatory Research and conventional research is in the area of power. Cornwall and Jewkes (1995) and Reid (2004) argue that in true participatory approaches, the control over the research process lies in the hands of the participants. They point out, however, that transferring power into the hands of the participants is not an easy objective to aim for and that many studies that are called participatory only achieve a small degree of success in this area. In fact, Gray et al. (2000)

question whether full participation is not more of a theoretical ideal than a true possibility. They suggest that a balance needs to be found between the theoretical ideals and the realities of the situation. Below, some of the difficulties that were experienced in this study in this regard are explored and these are compared to problems experienced by other research studies.

4.3.1 Power Imbalances: An Unequal Starting Point

Brugge and Kole (2003) point out that researchers come into a poor community with a high level of power compared to the participants, because of their background of education and access to resources. This may be further enhanced in the minds of the participants who may perceive the researchers to be the experts and lack belief in their own knowledge and abilities. This was the case in Low et al. (2000) - the participants assumed that the researchers were experts and thus wanted them to take control of the research process and even handle other problems outside of the research for them. Gray et al. (2000) also note a power imbalance in their study. They describe how this led to the participants of one group, agreeing to all their suggestions on how the research could be done, in spite of the fact that they were actually uncomfortable about the whole process. The participants did not, however, confront them about this. They simply agreed to everything and then took no further action in implementing the researchers' suggestions when they had left. It took quite some time and effort on the part of the researchers to uncover the true nature of the problem. This incident bears a similarity to what happened in the current study - the participants mostly agreed to the researcher's suggestions on how the research should be done, but later in the process it became evident that they were not entirely satisfied with this. For example, the researcher had told the participants in the beginning that they would be working together to solve a problem and the participants agreed to this. Towards the end of Participant Cycle 1, however, the group members expressed doubts about whether this would work. Gray et al. (2000) point out the need to be aware of this power differential when entering the research field. They advocate that researchers take special care to actively involve the participants in every aspect of the process, rather than just obtaining passive agreement to the researchers' agenda.

4.3.2 Contracting: The First Contact

The consent-taking process is often the first interaction that the researcher has with the participants and thus it has an important role in shaping the nature of the relationship between the researcher and participants and the roles that each take in the research process. In the previous chapter, a question was raised around whether the process of taking informed consent using a pre-prepared consent form, a model which evolved out of experimental research (Munhall, 1988), is the most appropriate and empowering way of engaging people in a PAR project. This procedure raises two important concerns. The first is that, in order for this process to work, the participants need to think through all the possible ramifications of involvement in the research, ask questions and voice any concerns that they have. Since PAR is usually conducted with groups that are marginalised and disempowered, it is, in fact, highly likely that

the participants will not have the skills and/or confidence to do this. The second is that this process is mostly a one-way process over which the researcher has control. The participants are not given the opportunity to share in the process of drawing up the contract. The lack of negotiation is contrary to the PAR principle of shared control and involvement of the participants in shaping the research process.

It seems likely that using this researcher-controlled, non-interactive process will have consequences for the research and empowerment process. It may reinforce the expectation in the minds of the participants that the researcher is in control and that they are simply expected to agree or disagree with whatever is presented to them, rather than taking an active role in shaping the process. It also emphasises the power differential between the researcher and the participants. It seems appropriate, therefore, that for this kind of research, alternative ways of engaging participants in the PAR process should be explored. Gray et al. (2000) points out that funders often require the details of a proposed research project to be spelt out before they will grant funding (this is often true of obtaining ethical clearance as well). This limits the possibilities for researchers to approach participants with an entirely open agenda and form the contract with them from the beginning. Meyer (1993) suggests, however, the concept of "process consent". This refers to re-taking consent as the process is adapted and changed. Thus it is not an alternative to the pre-prepared consent form, but it allows for flexibility and the involvement of the participants in shaping the process.

4.3.3 Facilitator Issues - "Letting Go of Control"

Kaplan and Alsup (1995) note that one of the potential obstacles in the transfer of power to the participants, is the inability of the researcher to "let go of control". They suggest that one of the reasons for this could be the researcher's ego. This, however, is not the only possible reason. Low et al. (2000) report that in spite of having a sincere desire to relinquish control to the participants, they found themselves unintentionally taking over control at certain points in their study. Sometimes this was due to pressure from the participants for them to take responsibility for certain tasks. At other times, this came out of the assumption that the participants would not be able to take responsibility for themselves. Low et al.'s (2000) experience bears similarity to what occurred in this study. Although the researcher valued the principle of transferring power to the participants, she found herself unintentionally taking control for similar reasons to those mentioned above.

Low et al. (2000) draw the conclusion that the power differential is not something that can be dealt with simply by having a sincere desire to do so or by commitment to principles of equity. Researchers need to be constantly alert to this dynamic and to reflect on how willing and able they are to surrender control to the participants (Kaplan and Alsup, 1995). In Low et al. (2000), the researchers reflected on their actions in between each group session and, if they felt they had taken too much control in the session, they attempted to correct this in the next session. Some examples are given of where the facilitators volunteered to take action on suggestions made by the participants. After reflection on these incidents, the facilitators decided they had assumed too much control and they attempted to rectify this by suggesting the participants take

responsibility for these actions at the next meeting. However, at times, the participants resisted this attempt to hand back the control to them. This raises another important aspect in power transfer, that of participant resistance.

4.3.4 Participant Resistance

Cornwall and Jewkes (1995) point out that PAR participants do not always want control of the process. Low et al. (2000) found that at times their participants wanted the researchers to take control and decide things for them. When given the opportunity to make decisions in the research, the participants were unsure of what to do and tended to agree with whatever the researchers had suggested (Low et al., 2000). Low et al.'s (2000) experience, bears similarity to the current study. The researcher found that the participants did not come up with ideas of their own, but tended to defer to the researcher's suggestions. In referring to a similar problem, Gray et al. (2000) suggest that researchers need to take extra time and effort to actively encourage participation in all aspects of the process. They note that because of the power differential between the researcher and the participants, the participants will tend to defer to the researcher's suggestions, rather than speaking up about their own. Gray et al. (2000) also observe that taking ownership of the project can be time-consuming and burdensome for the participants and that they may not be willing to take this on. They advocate, however, that researchers need to negotiate each aspect of the project with the participants, rather than simply assuming either that they want to be involved in all of it, or that they do not want to participate at all.

4.3.5 Learned Helplessness and Learned Hopefulness

Prilleltensky et al. (2001) observe that power and control are not inherited attributes that an individual either has or has not; they are qualities that are developed by continual interaction with the environment. "Learned helplessness" theory, proposes that exposure to uncontrollable events will tend to lead to individuals losing motivation and feeling helpless and out of control. In contrast, "learned hopefulness" theory proposes that if individuals are given opportunities to exert control over their lives, their motivation and sense of control and empowerment will increase (Zimmerman, 1990b). Participating in community organisations or projects that offer individuals opportunities to learn new skills and take part in decision-making, can facilitate the process of building "learned hopefulness" and consequently empowerment. Skills such as problem-solving, decision-making, time-management and other life skills can help individuals learn to cope better with their problems and thus feel more in control of their lives. This is referred to as "perceived control" and is an important part of the intrapersonal aspect of empowerment (Zimmerman, 1990b).

In the current study, all the participants come from impoverished backgrounds and have experienced a number of traumatic events in their lives over which they had no control (e.g. the death of loved ones due to HIV/AIDS, the loss of homes and financial security, rejection from friends and family etc.) According to the theories presented above, these circumstances

are likely to have led to the participants feeling powerless and lacking motivation. In this context, it is understandable that they should have developed a low sense of self-efficacy. This further explains why they resisted control being passed over to them, as having a low sense of self-efficacy, they lacked the confidence to take control and make decisions.

4.3.6 Low Self-Efficacy

According to Bandura (1997), people with low self-efficacy are likely to be demotivated, pessimistic about their chances of succeeding in life and are more likely to suffer from anxiety, sadness and depression. From the above description, it can be inferred that people with low self-efficacy are likely to lack the confidence and the motivation to participate in empowerment projects and if they do participate they are less likely to take an active part in the process. This presents a problematic situation: in order to be empowered people need to take part, but in order to take part they need to be empowered. Bandura (1997) describes four main ways of increasing self-efficacy. These include:

1. Giving people the opportunity to solve a problem successfully
2. Verbal encouragement and persuasion
3. Watching someone who is similar to themselves succeed at a task or successfully solve a problem
4. Building up physical strength and stress reduction

In this study, the researcher attempted to use the first two methods to increase self-efficacy and facilitate empowerment. The participants were not greatly convinced, however, that they could successfully act against the disabling circumstances in their lives and therefore their motivation to make an attempt was low. It seems that the idea was too overwhelming for them. It might, therefore have been better to start with a smaller and seemingly more attainable goal. Cornwall and Jewkes (1995) and Reardon et al. (1993) suggest that people can be encouraged to take on projects if their confidence is built up gradually by giving them small tasks and then increasingly larger responsibilities. Bandura's (1997) third and fourth methods of building self-efficacy might also have been helpful; for example, finding a creative way to introduce a successful role-model to the group and using stress management strategies. Possible strategies to minimise stress include: reducing the frequency and length of the focus group and/or to focus on action aimed at income generation.

4.3.7 Hope and Despair in HIV

Cochrane (2003) found uncertainty to be a predominant theme in the lives of people living with HIV/AIDS. This uncertainty was related to the unpredictable course of the disease and the experiences the participants had of recovering from serious illness to a sense of well-being, but never knowing when they would fall ill again. Participants in Cochrane's study described their

experience as being like a “roller coaster” (Cochrane, 2003, p 385). Uncertainty is a normal part of human existence. However, many people are unaware of it until something happens to make them aware of it (Cochrane, 2003). As pointed out in the previous section, the participants in this study had already faced a great deal of uncertainty due to other factors in their lives, before their diagnosis with HIV/AIDS. It seems that HIV/AIDS added another dimension to an already uncertain existence. In the previous chapter, the participants' experiences of hopelessness and despair alternating with moments of triumph and hope, were described. These findings are supported by the Kylmä et al. (2001, p 362) study, which found “living with fluctuating waves of hope, despair and hopelessness” to be a common experience of people living with HIV/AIDS. Positive experiences of coping with life were found to build hope, but deterioration in one's physical condition was said to bring on despair (Kylmä et al., 2001). These descriptions bear similarity to some of the experiences described by the participants in this study (see Appendix D on page 107).

Kylmä et al. (2001) point out that fluctuations between hope and despair can have serious consequences for people living with HIV/AIDS. When hope is dominant, individuals are likely to have energy and motivation, but when despair or hopelessness is the overriding factor, the opposite is likely. This has implications for the empowerment process. Kylmä et al. (2001) recommend that people working with people living with HIV/AIDS, should be acutely aware of these mood changes. They suggest that professionals ask their clients about their sense of hope and despair and use interventions that foster hope. These recommendations, though aimed at nurses in a clinical setting, are also relevant for the empowerment process. Knowing where the participants are on the continuum of hope and despair, could be important for structuring the research process as periods of despair could negatively impact on the participants' ability to take part in the process.

4.4 Facilitating Group Process

Smithson (2000) points out that group interaction forms an essential part of the data collection process in research using focus groups. Smithson (2000) discusses how group interaction can be useful for generating rich data, but also points out that there are a number of challenges in using this method. Some of these challenges are presented below.

4.4.1 Dominant and Passive Group Members

The problem of quieter participants not being heard is one of the issues raised by Smithson (2000). She suggests that certain participants may be reluctant to express their views if they differ from what the majority think. This may be particularly problematic in heterogeneous groups that contain a minority who are different from the rest of the group. In the current research, there was only one man in the group and four women. This dynamic may have discouraged the man from expressing some of his views. Nv and Nt were even quieter in the group sessions. It is not clear how much of this was due to their personalities and how much could be attributed

to group dynamics and/or other issues. Smithson (2000) suggests that the facilitator could intervene in this situation by asking the quieter members for their opinions and encouraging them and affirming their contributions. By doing this, the facilitator can make a way for the quieter participants to enter the discussion. This could have been done more often in the current study.

4.4.2 Conflict Resolution

Bryan et al. (2002) report that unequal power relationships were a major source of conflict in their study. They report that this was dealt with in the group process by using honest and open communication between the members. When a group member who held more power than the others asserted her authority, one of the other participants would comment humorously, "Hierarchy is raising its ugly head!" (Bryan et al., 2002, p 342). This became an important phrase with which the participants could challenge the power dynamics in the group. Honest communication of feelings and negotiation were used to solve conflicts, with each group member taking responsibility for expressing his/her concerns. In contrast to this method of conflict resolution, the participants in the current study did not raise their concerns with the researcher and instead expressed their dissatisfaction by withdrawing from the process. It is important to note, however, that the participants in Bryan et al. (2002) were educated, middle-class people and thus it is not surprising that they had more confidence in expressing their concerns than the participants in the current study. This raises the question of how the researchers can assist disempowered groups to be more assertive and voice their feelings about the group process.

In Bryan et al. (2002), the participants regularly reflected on the process and open discussion on what each member thought and felt was encouraged. In the current study, the researcher could perhaps have used this strategy in GRP4 and 5. She could have, for example, suggested to the participants that not coming to the group could be a way of expressing dissatisfaction with the process and asked them to comment on whether they thought this was the case. In Participant Cycle 2, the researcher did initiate a process of reflecting on what had occurred. She did this by expressing her feelings of confusion and disappointment over what had happened and this resulted in Nx telling the researcher about the payment issue. However, this reflection process came too late in the process and was too short to make a meaningful impact on empowerment. Thus the participants were not given an opportunity to learn better ways of dealing with the conflict.

Williams and Lykes (2003) also used a process of reflection to work through a conflict situation. They wanted to discover the reasons why the participants in their study did not take the action they had agreed to take (taking photographs in the community) after initially been very enthusiastic about it. The researchers expressed their disappointment to the participants and this was used as a starting point to initiate a reflection process around what had happened. Discussion and role-plays were used to depict what had happened and through this the reasons for the participants' lack of action were uncovered. The group members then discussed and role-played various ways of addressing these problems. This helped the women identify for themselves what the difficulties were and enabled them to express their fears, as well as helping

them to find acceptable solutions for themselves. The role-plays also gave the researchers insight into the women's cultural background and helped them discover how best they could enable the women to participate in the study. Role-play might have been effective in helping the participants in the current study, work through some of the conflict that occurred in the group and learn alternative methods of conflict management.

4.5 Crossing Language and Cultural Barriers

Accurate interpretation of participant responses is a challenge in any research and misunderstandings are always a potential problem. However, this risk is much greater in studies that involve a language barrier. A researcher who is not fluent in the participants' language is dependant on the skill and accuracy of the interpretation "instrument" - the translator (Esposito, 2001). Swartz (1998) points out that translation is not a simple process of converting words in one language into the equivalent words in another. Often concepts and metaphors in one language cannot be understood by simply translating them word for word. The interpreter is required to listen to the person's words, understand the non-verbal messages the person is giving and interpret the whole message in the context of the cultural background that the person comes from (Swartz, 1998; Herselman, 1994). Thus it can be seen that the interpreter plays a difficult role that requires a great deal of skill.

Swartz (1998) reports that in the South African context, interpreters are often required to play the role of cultural brokers in order to assist professionals from Western European backgrounds to understand the perspectives of their black clients whose backgrounds and culture are vastly different. Herselman (1994) explains the role of a cultural broker as being one of establishing "meaningful links" between people of different cultures. Through the cultural broker, information about cultural beliefs and behaviours can be conveyed, which can facilitate both parties understanding one another. Herselman (1994) studied consultations between medical staff and patients in a rural South African hospital. Herselman (1994) reports that while many interactions appeared on the surface to go smoothly, there were many subtle misunderstandings that took place, which left the patient feeling fearful and distrustful and often ended in non-compliance. The need for cultural brokerage is further highlighted by the Esposito (2001) study, where an experienced translator was employed who was not from the same cultural background as the research participants. This led to a number of misunderstandings because of differences in dialect, word usage and cultural meanings. As a result, Esposito (2001) advocates that a local translator who understands the dialect and the culture is employed. In this study, a translator with a very similar background to the participants, was employed, thus potential cross-cultural and dialect problems were avoided. However, the translator lacked the skills and experience to be able to play the role of cultural broker between the researcher and the participants effectively. Thus the researcher was not given the benefit of inside knowledge and understanding of the participants' culture.

Swartz (1998) advocates that both translators and professionals who need to make use of translators, should be trained in how best to conduct interviews and interactions that require

translation. He also makes some suggestions on how health practitioners and interpreters can improve the translated interview. Firstly, Swartz (1998) highlights the importance of preparation before the interview or interaction. Part of this preparation should involve the development of a mutually respectful relationship between the interviewer and interpreter, which allows for open communication and negotiation. The goals of the interview and the roles of the interviewer and the translator should also be discussed beforehand, as misunderstandings of these aspects can impact negatively on the process. Secondly, Swartz (1998) suggests that the interviewer should face the client and address the questions directly to him/her, as talking to the interpreter can impact negatively on the relationship developed between the interviewer and the client. Thirdly, fatigue and frustration need to be anticipated and the interviewer and interpreter should plan for the process to be slower than usual and to schedule breaks. Finally, discussion after the conclusion of the interview between the interviewer and the translator can be very helpful in giving the interviewer additional information about the client, including interpretation of non-verbal behaviour and cultural meanings of the client's words and behaviour (Swartz, 1998). These suggestions while aimed at health practitioners conducting interviews with clients, can also be helpful for examining what took place in this research and the making of recommendations for future research requiring interpretation.

In this study, the researcher employed an inexperienced translator and was herself inexperienced in working with a translator. The researcher was also unaware of many of the difficulties in translation work and as a result not enough consideration was given to the translation process. As Swartz (1998) suggests, more preparation before the focus group sessions could have been helpful in smoothing the process. In Participant Cycle 2, the researcher did some additional preparation with the translator in which she explained some of the concepts, which she wanted to discuss, before the time and thus the translator was able to think about and pre-translate these ideas. This appeared to help the translator a great deal and facilitate the translation process. Further preparation could also have been done through using role-plays to practise the translation process. Overall the translator and the researcher had a good relationship. However, it is possible that the translator felt a bit overawed by the researcher's superior education level and this may have impacted on her willingness to communicate certain information to the researcher. It might have been helpful for the researcher to work on this aspect of their relationship and to emphasise that she needed to learn from the translator. She could also have been more proactive in explaining what kind of cultural information and insight she wanted to gain from the translator instead of just asking her general questions about any observations she had made during the sessions. Allowing for breaks during the group sessions could have been helpful for both the translator and group members.

4.6 Conclusion

This chapter has explored a number of issues arising from the findings of the current study. These include: engaging people to participate in PAR; achieving participant control of PAR; facilitating the group process and crossing language and cultural barriers. These issues have been explored in relation to problems encountered in other PAR studies and some possible

solutions have been investigated. The chapter has also highlighted some particular challenges that need to be considered when dealing with people living with HIV/AIDS in the context of poverty. These include: problems related to the participants' pressing need for income generation; problems related to low self-efficacy; and problems related to the participants' fluctuating emotions due to their HIV/AIDS diagnosis.

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Chapter 5

Conclusions

5.1 Introduction

This study has described the challenges involved in facilitating the PAR process with a group of people living with HIV/AIDS in the context of poverty. These challenges have been explored in relation to the findings of other PAR studies and some alternative methods for dealing with these problems have been discussed. This chapter summarises the main outcomes of the study; the strengths and limitations of the research; the conclusions and recommendations; and the recommendations for further research.

5.2 Outcomes of the Study

The initial research question involved exploring how the participants could be empowered to find their own solutions to their problems. This question had to be altered after the participants withdrew from the study and it was no longer possible to answer it. The research question and the aims and objectives were changed to focus on exploring the challenges involved in facilitating the PAR process with the participants, a group of people living with HIV/AIDS in the context of poverty. The success of the study in meeting the new aims and objectives is evaluated below:

5.2.1 Objective 1: Participation and Participant Control of the PAR Process

An important principle of PAR is that the participants should be involved in all phases of the research (Cornwall and Jewkes, 1995; Babbie and Mouton, 2001). Gray et al. (2000) point out, however, that circumstances often limit the degree to which this is possible. In the current study, the participants were very involved in some phases of the research, but their involvement in others was limited by the short time frame of the study and their withdrawal from the research. The level of participation in each phase of the research is described below:

- **Research design:** The participants were not involved in the initial research design. However, the research was designed to be flexible so that the participants could be involved in shaping it to their particular needs.
- **Data collection:** The participants were very involved in the data collection process, although they took a less directive role as the researcher determined the questions. However, these questions were designed to be broad and general so that the participants could direct the discussion to the issues that concerned them
- **Analysis and utilisation of the results:** The participants withdrew from the research before the analysis process started. The researcher, therefore, analysed the data and presented the findings to the participants. They were then given the opportunity to comment on these and they were consulted on the utilisation of the results. The participants also decided to take part in distributing the results (see Section 3.6 on page 43).

5.2.2 Objective 2: Increased Self-awareness and Empowerment

The participants were given the opportunity to talk about and reflect on their circumstances and needs in the group sessions and to benefit from the therapeutic effects of the group discussion (see Section 3.5.1 on page 42). The participants were also given feedback from the researcher on the information they had shared. The feedback was on the following themes (see Section 3.7.2 on page 45 for further details):

1. **Validation of the Participants' Strength, Courage and Positive Attitudes:** The researcher told the participants that she had noticed that they had shown incredible strength and bravery in facing their problems in the past. The purpose of this feedback was to encourage the participants by pointing out their positive qualities.
2. **Acknowledgement of Their Sufferings and Grievs:** The researcher gave the participants feedback about the times of suffering and grief that they had shared with her. Through this feedback, the researcher aimed to acknowledge the participants' experiences and feelings and show empathy towards them.
3. **Explanation of Elisabeth Kübler-Ross's Stages of Grieving:** The researcher explained the stages of grieving to the participants in order to validate their experiences and reveal to them that the confused emotions that they had experienced were a normal human response to grieving and not a sign of weakness or abnormality.
4. **Knowledge, Attitudes, Skills and Resources.** The researcher pointed out to the participants that they had knowledge, attitudes, skills and resources, which they could use to protect themselves against the destructive influences of HIV/AIDS. The purpose of this feedback was to point out to the participants what they already had, which could help them in their situation and to encourage them to reflect on how they could use this to their best advantage.

The participants appeared to appreciate the feedback and find it encouraging. It is difficult, however, to assess how much these factors affected their self-awareness and empowerment as this was not assessed in the group.

5.2.3 Objective 3 and 4: Recording of the PAR Process and Highlighting Challenges

This study presents a detailed record of the PAR process, highlighting the challenges involved in the process. Recommendations for future PAR research are also given (these are summarised in Section 5.4). The results of this study will be further distributed through the following means:

- Publication of a journal article to inform researchers intending to implement PAR
- Publication of a magazine article to inform people living with HIV/AIDS
- The participants intend to further distribute the results by talking to people they encounter in their work (see Section 3.6 on page 43)

5.3 Strengths and Limitations of the Study

This study encountered a number of difficulties, which resulted in the outcomes of the research being very different from what was intended. However, the research process was successfully adapted to present useful insight into the PAR process and the challenges involved in implementing this kind of research. Below the strengths and the weaknesses of the research are presented.

5.3.1 Strengths

The strengths of this study include

1. A commitment to understanding the perspective of the participants and representing their voices as accurately as possible.
2. Critical analysis of the PAR process highlighting the weaknesses as well as the strengths of the research and not covering up researcher errors.
3. The presentation of feedback to the participants on the information that they shared.
4. Recommendations for future research on how to deal with the challenges of implementing PAR.

5.3.2 Limitations

The limitations are as follows:

1. The premature withdrawal of the participants from the research process limited the impact of the study and the potential of the research to be used to inform future studies on the empowerment process. Thus the study is limited to giving insight on the challenges of the PAR process.
2. The participants' words were not transcribed and analysed in their own language, thus subtle nuances of meaning may well have been lost through the translation process. The study is therefore limited in its ability to describe the participants' experience and the richness of the participants' descriptions is muted.
3. Many of the cultural meanings of the participants' words and behaviour may have been overlooked due to the researcher's ignorance of their culture. Furthermore, the cultural barrier may have led to the participants misinterpreting the researcher's words and behaviour. These dynamics were not explored in the research and this limits the richness and depth of meaning that can be drawn from this study.
4. There was limited feedback given by the participants on their experience of the PAR process and thus it is not possible to understand the experience from their perspective. Thus the study is limited to giving mainly the researcher's perspective and interpretation.
5. The participants' levels of empowerment were not measured either before or after the research study and therefore it is not possible to evaluate the impact of the study on the empowerment process (whether positive, negative or negligible).

5.4 Conclusions and Recommendations

This study has highlighted the challenges involved in implementing PAR. In this section, the conclusions of the study are outlined and from these, recommendations for future studies are given. The conclusions and recommendations are divided into the following categories:

- Engaging Participants in PAR
- Promoting Active Participation and the Transfer of Power
- Facilitating the Group Process
- Crossing Language and Cultural Barriers
- Special Considerations for Projects Involving People Living with HIV/AIDS in the Context of Poverty

5.4.1 Engaging Participants in PAR

In this section, the findings of this study with regard to how participants can be engaged in the PAR process are highlighted and from these findings, recommendations for future PAR studies are given.

- This study offered the participants an opportunity to take part in an empowerment project aimed at helping them find ways of meeting their own needs. While the participants were enthusiastic about taking part in this process and gaining the benefits offered, it was found that they were not prepared to invest their time in the study if there were not other incentives such as payment. It is, therefore recommended that researchers pay particular attention to the needs of the participants and negotiate incentives with them.
- In this study, the researcher could not afford to pay the participants, but found that providing food at the research meetings was an effective way of motivating them to attend. It is, therefore, recommended that researchers explore other possibilities for motivating participants to take part in PAR, in cases where it is not possible to pay them or when payment is minimal (e.g. initiating activities aimed at income generation (Prestby et al., 1990)).
- In this study, the participants' perceptions of the benefits and costs involved in taking part in the research changed when they discovered that they would not be paid for their time and as a result their motivation dwindled. It is important not to assume that the participants will stay motivated to be involved. Motivation is likely to fluctuate (Cornwall and Jewkes, 1995) and therefore continual monitoring of this is needed. The researcher may need to offer additional incentives or assist the participants with managing new costs which may arise during the process.
- The participants in this study did not have the confidence and the skills to articulate their expectations in the contracting process and negotiate terms that were agreeable to them. As a result, a misunderstanding developed between the participants and the researcher. It is, therefore recommended that researchers anticipate that the participants may have unspoken expectations and explore ways of helping them articulate these.
- In this study, the participants were expecting the researcher to provide benefits such as sponsorship, payment, support and advice. When these benefits were not provided, the participants lost interest in the research. Negotiating a compromise in this area might have succeeded in keeping them involved. It is therefore recommended that researchers negotiate with the participants around their expectations and be willing to be flexible and negotiate a compromise where these expectations conflict with the intended goals of the research.
- In this study, the researcher entered the research field under the auspices of another project and, as a result, the participants made some wrong assumptions about the nature of the relationship between the researcher and the other project. This contributed to the

participants assuming that they would be paid for their time. Researchers who enter the research process in partnership with other projects, are therefore recommended to anticipate misunderstandings and to be explicit about the nature of their relationship with these other role-players.

5.4.2 Promoting Active Participation and the Transfer of Power

Cornwall and Jewkes (1995) argue that PAR should involve the participants taking control over the research process. However, they point out that transferring control to the participants is a difficult process, in which many studies fail to achieve much success. In this study, the researcher did not achieve the success she had hoped for in transferring control to the participants. The reasons for this are described below and recommendations for future studies are given.

Problems in the Research Design: The Contracting Process

In this study, the participants were engaged in the PAR process through the taking of informed consent using a pre-prepared consent form. In hindsight, this is not thought to be the most empowering method of engaging participants in PAR as it does not allow for much participant involvement. The participants in this study also lacked awareness of their rights and responsibilities in the process and the confidence and skills to take full advantage of the opportunity to ask questions, express dissatisfaction and negotiate for terms to be changed. It is therefore recommended that researchers explore alternative methods of contracting and obtaining informed consent, which promote the active involvement of the participants and enable them to negotiate the terms and conditions they want. The contract between the participants and the researcher should be kept open and flexible should the participants' circumstances and needs change.

The participants were more actively involved in the process of forming a group contract, than in the consent-taking process. However, they again lacked the knowledge, skills and confidence to participate effectively and ended up taking on responsibilities they did not have the skills to carry out. Thus it is suggested that researchers evaluate the skill levels of the group they are dealing with, and based on this assessment decide on how much support and assistance the participants need in drawing up a group contract and implementing it. The group members also need to be reminded of the terms that they have drawn up throughout the process.

Facilitator Issues: "Letting Go of Control"

In this study, the researcher found that she tended to take back control from the participants, sometimes as a result of pressure from the participants and at other times, because of her lack of confidence in the participants' ability to take control. It is recommended that researchers reflect on their words and actions after each group session and assess whether they are taking

back control from the participants unnecessarily and then take steps to correct this in the next session, as was done by Low et al. (2000).

Participant Resistance

Cornwall and Jewkes (1995) point out that participants may not necessarily want to take control of the research process. This may be because of low self-efficacy and self-confidence or because they feel it would take up too much time and energy. It is recommended that researchers bear this in mind when initiating the PAR process and do not overwhelm participants with too much responsibility, but negotiate with the participants with regard to how much they feel willing and able to take on initially. (The issue of low self-efficacy is further discussed under Section 5.4.5)

5.4.3 Facilitating Group Process

In the previous chapter some of the problems that occurred in the group process were identified and possible solutions from the literature were explored. Below conclusions and recommendations drawn from the researcher's experience are presented:

- While the participants were from similar socio-economic and cultural backgrounds, there were many differences between them. These include: differences in age, gender, family make-up, health status, time since diagnosis with HIV etc. These differences provided rich data, but also appeared to lead to some underlying tension, which did not lead to open conflict between group members, but appeared to affect the cohesiveness of the group. It is suggested that researchers help the participants to reflect on group process and assist them to deal with tensions and conflicts constructively (compare with Bryan et al., 2002).
- Reflection on group process might have also been helpful for dealing with the misunderstandings that took place between the researcher and the participants. The researcher could have made observations about what she perceived to be happening, to initiate this process (e.g. "Sometimes people do not attend meetings when they are unhappy with what is taking place. Do you think this could be the reason why some people are not attending?")
- One participant was particularly dominant in this study. While her contributions were valuable, at times her dominance had the effect of discouraging some of the quieter participants from giving their views. It is, therefore, recommended that researchers encourage quieter participants to contribute by asking their opinions and affirming their contributions.
- The researcher made a number of mistakes in facilitating the group process, but she learnt from these and improved with time. It is recommended that researchers reflect on their facilitation skills and attempt to learn from their errors. It is also suggested that inexperienced researchers are mentored by more experienced researchers.

5.4.4 Crossing Language and Cultural Barriers

Language and cultural barriers presented major challenges to the research process. Below, these challenges are explored and suggestions are presented relating to how these can be managed:

- An inexperienced translator was employed in this research as giving the opportunity to someone from a disadvantaged background was considered to be in line with the ethos of the research. The translator also came from a similar background to the participants and this was thought to be advantageous as it would enable her to identify with the participants. This did appear to be beneficial as a good relationship was established between the translator and participants. However, the inexperience of the translator probably played a role in the misunderstandings that developed between the researcher and the participants. It is, therefore, recommended that if an inexperienced translator is employed in PAR, researchers should set aside additional time for preparation and assisting of the translator to perform his/her role effectively. Ideally, the translator should also be mentored by a more experienced translator and his/her work should be checked for errors.
- In this study, spending time preparing for the session with the translator was found to be beneficial. In this time, the researcher was able to explain unfamiliar terms to the translator and explain what she wanted to achieve in the session. It is suggested that researchers who work with translators set aside time for preparation. The preparation time could also be used to practise the translation process through role-play. This could be beneficial for the researcher as well as the translator as the skill of working with a translator also requires practice (Swartz, 1998).
- Swartz (1998) suggests that a translator can perform the function of a cultural broker. Had this happened in this study, some of the misunderstandings which occurred might have been avoided. It is suggested that researchers doing cross-cultural research anticipate that misunderstandings may take place and make use of whatever resources they have available to help them understand the cultural differences. An experienced translator may be able to perform this function adequately. Alternatively, the researcher could consult with an expert.
- In this study, the translation process was found to interrupt the conversation flow and make it difficult for interactive group discussion to take place. It is recommended that researchers bear this in mind when planning research involving translation. Some suggestions for managing this problem are:
 - Employing a translator who also has facilitation skills so that he/she can facilitate the discussion in the alternate language.
 - Making use of translation equipment that allows simultaneous translation (see Esposito, 2001).

5.4.5 Special Considerations for Dealing with People Living with HIV/AIDS in the Context of Poverty

This study involved a group of people living with HIV/AIDS in the context of poverty. For these people, HIV/AIDS is a compounding factor which is adding to their already difficult situation. Not only do they not have the resources they need to provide for themselves and their families under normal circumstances, but they also not have the extra reserves required to meet the additional demands that HIV/AIDS places on their lives (Van der Vliet, 1996). Working with this group of people held particular challenges for the PAR process. Below these are highlighted and recommendations are given.

Problems Relating to the Participants' Pressing Needs for Income Generation

For the participants in this study, investing time in the research meant giving up time that could have been used for income generation. Rifkin (1990, as cited by Cornwall and Jewkes, 1995) points out that people who are struggling to secure the basic necessities of life are likely to be reluctant to invest their time and energy in activities which do not satisfy their basic needs. It is recommended that researchers bear this in mind when dealing with people living in poverty. This problem could be approached by reducing the amount of time required for participants to invest in the study and/or compensating the participants for their time.

Problems Relating to Low Self-efficacy

The participants in this study, did not see themselves as being capable of solving their own problems and they expected the researcher to provide solutions. The researcher attempted to address this by encouraging the participants and reassuring them of her belief in their capabilities and by explaining to the participants that she did not have the solutions to their problems. However, verbal encouragement was not sufficient to change the participants' self-perception and give them the confidence to participate actively. Initially, they continued to place confidence in the researcher's ability to solve their problems and when they realised that this was not going to happen, their confidence waned and they were left feeling uncertain and sceptical of the possibilities for a successful outcome. This uncertainty may well have played a part in the participants' withdrawal from the research. It is, therefore recommended that researchers anticipate that participants may not be ready to take an active part in the research immediately. The research process may therefore need to be adapted to allow time for the participants' confidence to be built up before they are ready to take on responsibility for the process. Some suggestions for building self-efficacy are:

- Verbal encouragement and persuasion (Bandura, 1997)
- The participants' self-efficacy can be built by watching a role-model succeed at a task (Bandura, 1997).

- Giving the participants small responsibilities to build up their confidence and then gradually progressing to larger tasks (Cornwall and Jewkes, 1995; Reardon et al., 1993)
- Building up physical strength and stress reduction (Bandura, 1997).

Fluctuating Emotions related to Their HIV/AIDS Diagnosis

In this study, the participants described experiencing fluctuating emotions that swung between hope and despair. This was similar to the experiences described by the participants in Kylmä et al. (2001). It is recommended that researchers are aware that the participants living with HIV/AIDS may experience these fluctuations and that periods of despair are likely to affect the sufferer's energy levels and motivation. It is also suggested that the researcher asks the participants about their experiences of hope and despair and takes these into account when planning research activities and interventions (as suggested by Kylmä et al., 2001).

The Importance of Memory Boxes

All the participants in this study reported that they had found the process of making memory boxes valuable. Some of them spoke about how it had helped them to release "stress" and pent up emotions (see Section 3.8.5 on page 55). Memory boxes are therefore recommended as a valuable resource for people living with HIV/AIDS (see Morgan, 2001 for further details).

5.5 Recommendations for Further Research

This study has highlighted a number of important concerns and challenges that impact on the PAR and the empowerment process. It is recommended that further research is done in these areas as there appear to be gaps in the literature in this regard. These areas of concern include:

5.5.1 Attracting disempowered people in poverty-stricken circumstances to take part in low budget empowerment projects.

In order for people to benefit from empowerment projects they need to participate in these initiatives. However, as has been shown by this project, people in poverty-stricken circumstances are unlikely to participate unless they are given some kind of compensation or reward for their efforts, which contributes towards their struggle for survival. This can be problematic as many projects lack the budget to give significant financial compensation. It is therefore recommended that research is undertaken on how people can be attracted to participate without huge economic outlay. This could involve studies which investigate how people's motivation is effected by non-material benefits and how these could be marketed to potential participants.

5.5.2 How to contract with the participants in an empowering and participatory manner.

In the current study, a particular area of concern was the contracting process. It was found that the contracting method used was not sufficiently participatory and an opportunity for empowerment and skills transfer was missed. It is recommended that further research is undertaken on how to make this process more participatory and empowering.

5.5.3 Power relations in PAR

Handing over control to the participants is a vitally important objective of PAR as it is through this process that the participants are empowered and given the opportunity to learn new skills. However, in this study, this process was blocked by a number of problems, including, resistance from the participants and their lack of confidence in themselves. It is therefore recommended that further research is done on how this process can be effectively implemented and how the barriers can be overcome.

5.5.4 Issues involved in crossing language and cultural barriers in PAR

In this study, a number of problems were encountered in the area of crossing language and cultural barriers. This resulted in some misunderstandings and also difficulty in translating and interpreting the results of the research. It is recommended that further research is done into this area as cross-cultural and multilingual research is a vitally important and necessary process for extending knowledge about different cultures and language groups.

5.6 Conclusion

PAR methodology offers an exciting alternative to the more traditional top-down, researcher-controlled approach and holds out the possibility of achieving more effective and sustainable outcomes for communities. However, as this research has highlighted, there are many challenges involved in implementing the PAR process. This research has described some of these challenges and made some recommendations for future PAR studies.

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Appendix A

Documents

The following documents are included in this appendix:

- English consent form
- Xhosa translation of the consent form
- Letter from the UCT Health Sciences Ethics Committee giving approval for the study.

A.1 English Consent Form

The following information is provided to help you decide if you want to take part in this study. You do not have to take part if you don't want to. You will not be discriminated against in any way if you decide not to take part and you will still be able to be part of the Memory Box Project. If, at any stage, you change your mind, you are free to withdraw from the study.

This study is a Participatory Action Research project - that means you will take part in all stages of the research and you will also have a say in how the research is done. We will be gathering information about your needs and experiences in relation to being HIV positive. We will then use the information we have gathered to take action aimed at meeting some of these needs.

The study will take place over a period of 3 months (June to August 2003). The research will be done in a group. (It may be the same group that you are doing the Memory Box Project with, if everyone agrees to take part). I can't give you a full description of what the study will involve, because a lot of it is going to depend on what you and your fellow group members decide you want to do. But here is a general description:

1: At our first meeting, we will decide things like how often we are going to meet and for how long. We will also decide on what the rules for the group will be (e.g. respecting one another's confidence) 2: The first few meetings, will involve you exploring your own and each other's experiences. We will be using exercises similar to those you have used in the Memory Box Project. 3: We will then start to discuss what needs each of you have. We will look at the similarities and differences. We will also look at your resources, strengths and abilities. 4: We will then identify a need or needs that all of you as a group want to work on. (We will try to reach

consensus rather than vote on this need). 5: Then we will come up with a plan of action and put the plan into practice. 6: The final task will be to evaluate the process.

We won't necessarily follow all these steps in order. We may skip some of them and repeat others. It will all depend on what the group decides. If, at any stage, there are major changes to the process, I will ask for your consent again. If you don't feel comfortable with what we are doing, you are free to withdraw at any stage.

I will be writing the results in my Master's thesis. Your name will not be in the research report and I will ensure that there is nothing in the project, which will give away your identity. You will be asked to read what I have written to ensure that it is a true account of what has happened. I will be tape-recording the group meetings. These tapes will be kept in a safe place. Only I, my co-facilitator and one other person who will be typing out what was said, will have access to these tapes. The typed record of the tapes will not have your name on it.

Some of the benefits you may gain from this project are: 1. Critical thinking and problem solving skills 2. Increased self-knowledge and self-confidence 3. Opportunity to learn from the experiences of the others in the group 4. Opportunity to take action against some of the problems in your life, with the support of the group behind you. I can't guarantee that you will gain any of these benefits, but every effort will be made to make this an enjoyable and worthwhile experience for you.

We will be talking about issues, which may be sensitive or painful for you. The project is not intended to cause you any distress, but, should you feel unhappy at any time during the study, please do not hesitate to speak to me about it. If I am not able to help you, I will refer you for counselling if you wish and/or you can withdraw from the study at this point. You will not be put under pressure to share anything about yourself in the group, that you don't wish to share.

Please do not hesitate to ask me any questions that you have. You are welcome to ask questions before signing this form or at any point during the study. You can contact me, Wendy Butchart, on: 0723833245 or 6899144.

If you wish to take part in this study, please sign this form. A copy of the form will be given to you to keep.

I _____ agree to take part in this study. I understand the purpose and nature of the study, which was explained to me by the researcher (Wendy Butchart). All explanations have been given in the language of my choice either by the researcher or through an interpreter. I have been made aware of all the possible risks and benefits that could be incurred as a result of being involved in this study. I have been given an opportunity to ask questions and I am aware that I am under no obligation to take part in this study. I am aware that there are no negative consequences for me if I decide not to take part and that I am free to withdraw from the study at any stage.

Participant's signature _____ Date _____

Researcher's signature _____ Date _____

A.2 Xhosa Translation of the Consent Form

Le nkcazelo ilandelayo yenzelwe ukukunceda wenze isigqibo sokuba uyafuna na ukuthatha inxaxheba kolu phando. Awunyanzelekanga ukuba uthathe inxaxheba xa ungafuni. Awuzukucalulwa nokuba ugqibe ekubeni ungathath inxaxheba kwaye usavumelekile ukuba ubeyinxalenye yeprojekti yeMemory Box. Usengarhoxa nanini na utshintsha izimvo malunga nokuthatha inxaxheba.

Le yiprojekti yophando ngentsebenziswano lo nto ithetha ukuba uya kuthatha inxaxheba kuwo onke amaqanaba ophando kwaye uyakuba negalelo kuhlobo uphando olwenziwa ngalo. Sakube siqokelela ulwazi ngeemfuno zenu neziganeko ezinehleleyo ngokuphathelelene nokuphila nentsholongwane kagawulayo. Sakuthi ke sisebenzise olo lwazi siluqokeleleyo ekuthatheni unyawo olujongise ekuhlangabezini nezinye zezingxaki.

Le projekti izakuthatha ixesha elingangenyanga ezintathu (June August 2003). Oluphando luzakwenziwa kwiqela labantu. (Isenokuba leliqela lenza iprojekti yeMemory Box ukuba bonke abantu bayavuma ukuthatha inxaxheba). Andikwazi ukunika inkcazelo epheleleyo ngezinto ezizakwenziwa kule projekti kuba izinto ezininzi zizakuxhomekeka kwisigqibo seqela elo ngezinto elifuna ukuzenza. Kodwa ke nazi ezinye zezinto eziza kwenziwa:

1: Kwintlanganiso yokuqala sizakuthatha isigqibo malunga namaxesha okudibana 2: Iintlanganiso ezimbalwa zokuqala zizakunxulumanisa wena uziphonononga amava akho nawabanye abantu. Sizakusebenzisa umgaqo ofana nqwa nalowa ubusetyenziswe kwiprojekti yeMemory Box 3: Emva koko sizakuxoxa ngezidingo zomntu ngamnye. Sizakujonga izinto ezifanayo nezahlukeyo kwezo zidingo. Sizakuphinda sijonge iindawo zoncedo, amandla esinawo nezinto esinako ukuzenza. 4: Sizakuthi sijonge imfuno okanye iimfuno eninokuthi njengeqela labantu nisebenze ngazo. (Sizakuzama ukuba sibe nesivumelwano ngalendima) 5: Emva koko sizakuza nesicwangciso esizakusetyenziswa size isicwangciso eso sivavanywe. 6: Uxanduva lokugqibela luzakujonga ukuba isebenze njani na iprojekti.

Azokulandela onke lamanqanaba ngokulandelelana kwawo. Sisenokusebenzisa amanqanaba athile, amanye siwaphinde. Konke kuyokuxhomekeka kwisigqibo esithatyathwe liqela. Ukuba kuthe kwabakho etshintsho olungamandla kule nkqubo, ndiyakuthi ndicele imvume yenu. Kwakhona ukuba akuziva ukhululekile yilento siyenzayo, uvumelekile ukuba ungarrhoxa nangaliphina ixesha.

Ndizakubhala iziphumo kwizifundo zam (Masters thesis). Igama lakho alizokubakho kwincwadi yophando kwaye ndizakuqinisekisa ukuba akukhonto kwiprojekti ezakuthi inikezele ngegama lakho. Ndizaninika ithuba lokuba nifunde endikubhalileyo ukuqinisekisa ukuba kuyinyani kwaye kuyinto ebithe yenzeka kwiqela. Ndizakushicilela kwitape iintlanganiso zamaqela. Ezotape zizakugcinwa kwindawo ekhuselekileyo. Ndim, umncedisi wam kwakunye nomntu ozakubhala into ethethiweyo abaya kufikelela kwezitape. Igama lakho alizokubakho kulemibhalo. Ezinye zezinto oyakuzizuka ngokuthatha inxaxheba kuleprojekti zezi: 1. Ukucinga ngokubanzi ngokusombulula iingxaki 2. Uzakufumana ulwazi ngesiqu sakho kwaye uzithembe 3. Iithuba lokufunda ngamava abanye abantu abalapha kwiqela 4. Iithuba lokuthatha amanyathelo ngezinye zengxaki kubomi bakho ngoncedo lweqela. Akukho siqinisekiso sokokuba uyakuzizuka zonke

ezizinto, kodwa zonke iinzame zizakwenziwa ukuze wonwabe kwaye ufumane amava angawo.

Sizakuthetha ngemiba echukumisayo okanye enokuthi ikukhathaze. Le projekti ayinanjongo yokukhathaza yaye xa uziva ungonwabanga nangaliphi na ixesha lalenkqubo nceda ungathandabuzi ukundazisa ngoko. Ukuba andinako ukukunceda ndiyakukuthumela kwindawo yoncedo, kungenjalo usenako ukurhoxa kulenkqubo. Akuyi kunyanzeleka ukuba uthethe ngezinto ongafuni kwabelana ngazo kwiqela lakho.

Nceda ungathandabuzi ukundibuza nayiphina imibuzo onayo. Wamkelekile ukubuza imibuzo ngaphambi kokuba utyikitye le fomu okanye naphakathi kwinkqubo. Ungaqhagamshelana nam, Wendy Butchart, kule nombolo 0723833245 okanye 6899144.

Ukuba unomdla wokuthatha inxaxheba kulenkqubo, nceda utyikiye lefomu. Ikopi yefomu uyakuyinikwa uzigcinele.

Mna _____ ndiyavuma ukuthatha inxaxheba kulenkqubo. Ndiyayiqonda injongo nohlobo lwalenkqubo oluthe lwacaciswa kum ngumphandi uWendy Butchart. Zonke ingcaciso zithe zacaciswa ngolwimi lwam ngumphandi okanye yitoliki. Ndilumkisiwe ngezinto ezingenzeka nangenzuzo endingazifumana ngokuthatha inxaxheba kulenkqubo. Ndililiniwe ithuba lokubuza imibuzo kwaye ndiyazi ukuba andibophelelekanga ukuba ndingathatha inxaxheba kulenkqubo. Ndiyazi ukuba xa ndithe andathatha inxaxheba kulenkqubo okanye ndirhoxe nangaliphi na ixesha akukho ziphumo zibi ezinokundehelela.

Umthathi nxaxheba _____ Umhla _____

Umphandi _____ Umhla _____

A.3 Ethics Approval Letter

UNIVERSITY OF CAPE TOWN



Research Ethics Committee
Faculty of Health Sciences
OMB E46 Room 26, GSH
Queries : Xolile Fula
Tel : (021) 406-6492 Fax: 406-6411
E-mail : Xfula@curie.uct.ac.za

03 March 2003

REC REF: 049/2003

Ms WA Butchart
Nursing & Midwifery

Dear Ms Butchart

EMPOWERING PEOPLE LIVING WITH HIV/AIDS: A PARTICIPATORY ACTION RESEARCH STUDY

Thank you for submitting your study to the Research Ethics Committee for review.

It is a pleasure to inform you that the Ethics Committee has formally approved your study on the 6th March 2003.

Please quote the Reference number in all correspondence.

Yours sincerely

A handwritten signature in black ink, appearing to read 'A. Swanepoel', written over the typed name.

A/PROF. CR SWANEPOEL
CHAIRPERSON

Appendix B

Presentation of Feedback to Participants

This appendix contains the posters that were used to present feedback to the participants (see Section 3.7.2 on page 45 for further details). It includes the following:

- The “life road”
- The four quadrants of the “shield”:
 - Knowledge
 - Attitudes
 - Skills
 - Resources
- The “cartoon summary”

B.1 The “Life Road” Poster

(Please turn to the next page for the “life road” poster)



KNOWLEDGE

Strengths

MYSELF

Weaknesses

HIV



HOW DO I FIGHT IT?

FAMILY COMMUNITY

How can I
make it easier
for them?

How can I
help them
understand?



FUTURE

What can I do today
to make tomorrow

no fear
 FURTHER
 out of control
 fear

loneliness
 fear
 angry
 hurt
 rejection

loneliness
 hurt
 rejection
 acceptance
 support
 understanding
 love
 longing

FAMILY

support
 understanding
 want help
 COMING



WASTELAND

ATTITUDES

SKILLS

- Teaching
- Listening
- Writing

University of Cape Town

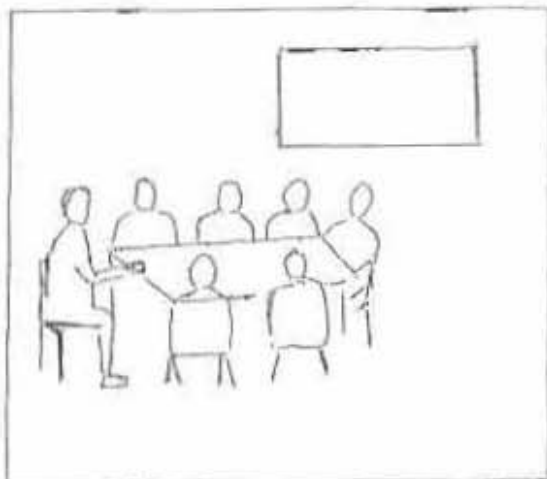
RESOURCES

• Memory box

• Family

• Support group

B.3 The "Cartoon Summary"



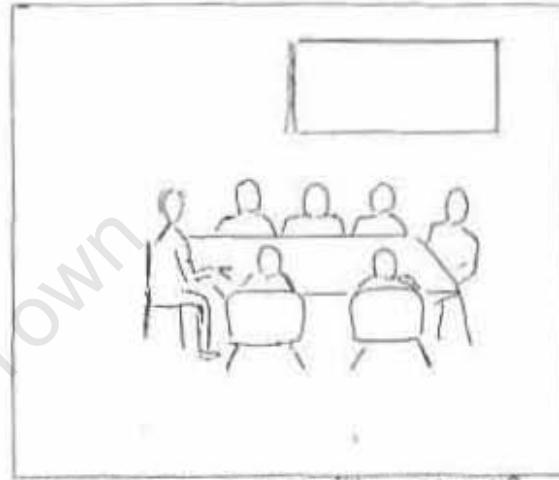
W: What is research?

Nx: Research is something that can help people

X: Someone looks for something

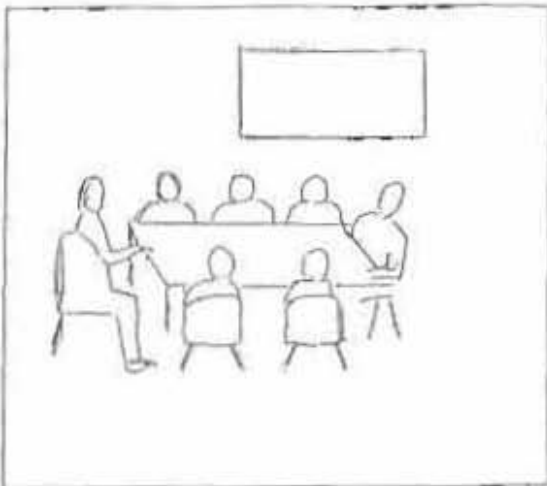


W: Research is about asking questions and finding answers.



L: What are you going to do with our answers?

W: What do you want me to do with your answers?



L: Tell the tourists at UCT and they will sponsor us.

Nx: Give us support and advice

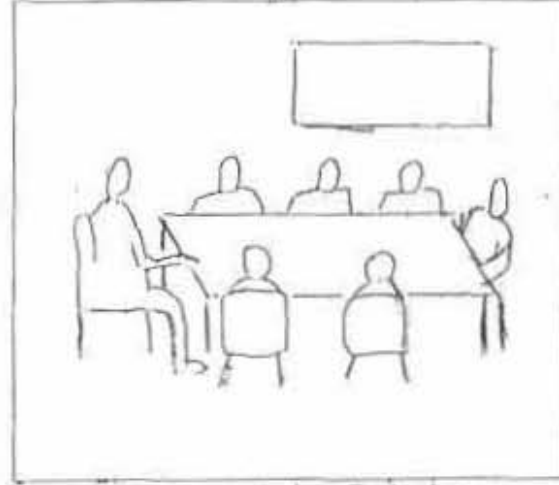
W: You are hoping this research will help you?

Group: Yes



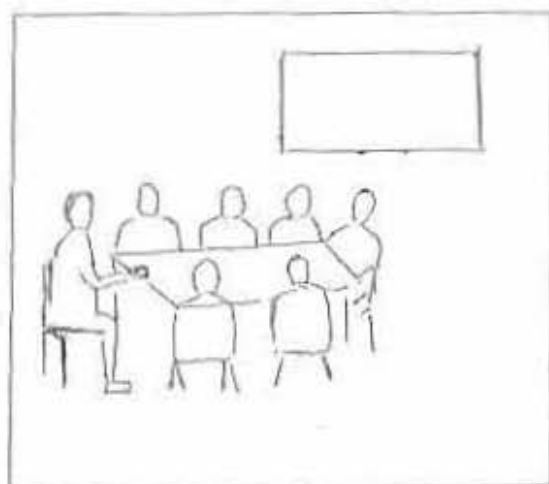
W: Who does research?

Nx: People from England or America



W: Really? But I am not from England or America! I am from Cape Town.

L: But you are not from here! You are not from Masiphumalele.



X: Can people from Masiphumalele do research?

W: What do you think?



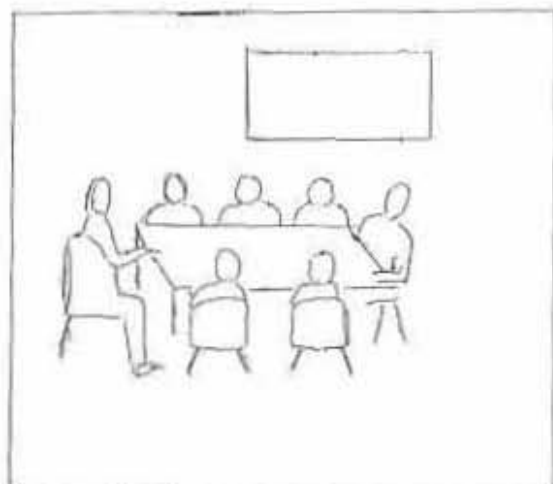
Nx: Yes I think they can. We have home visitors who ask questions about our lives.

W: Can anyone do research or do they need special training first?



X: I think they need special training

W: What skills do you think a researcher needs?

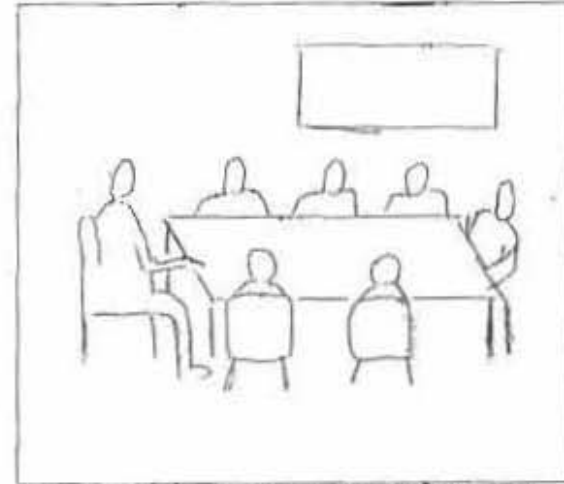


Group: Respect....Knowledge....Problem solving....Listening....

W: That's right. You already have some of these skills and you are busy learning more.



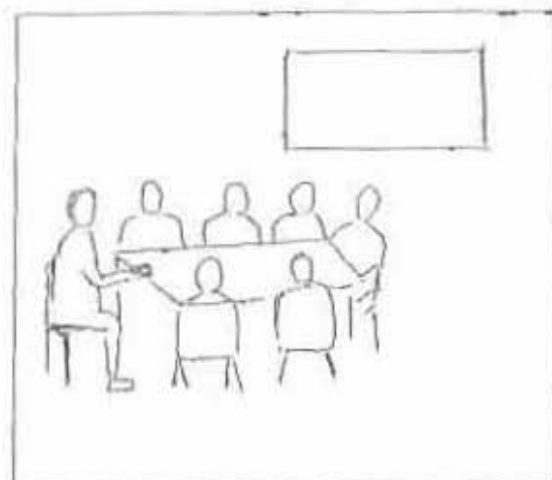
W: That's what is different about this research. It's not about me doing research on you or about me doing something with your answers. It is about us doing something together. You all have knowledge and skills....



W: What do you feel about doing research like this?

L: I feel great, because I can help people.

Nx: I think this research is important for our lives.



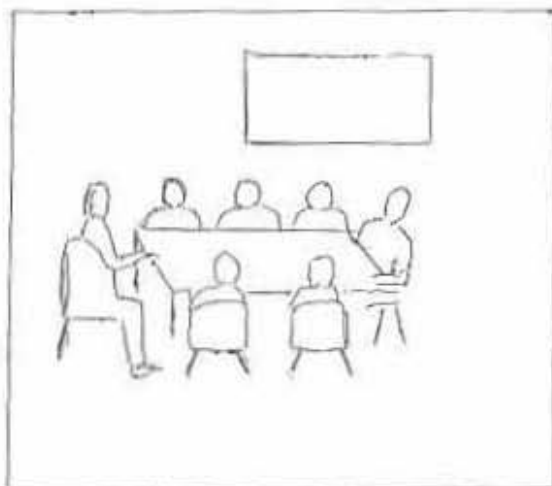
W: How are you all today? Do you have any questions?
Group: Fine. No questions.



W: What are your needs?
Group: Houses... good food ... jobs ...
ids... money for children... acceptance from family and community...



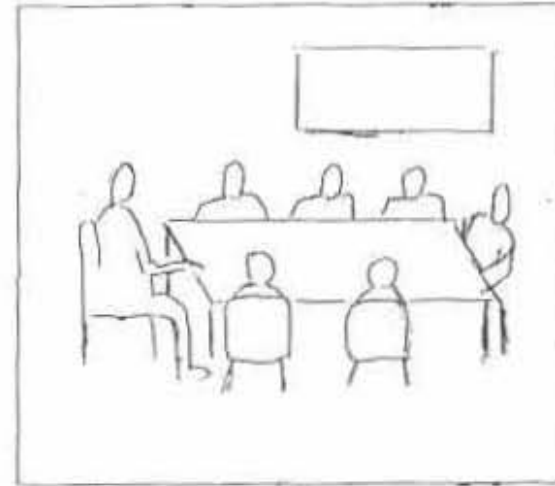
W: Can you tell me about your memory boxes?
Nx: I think it is important for people with HIV. It takes away the stress!



W: Can you tell me about a page in your memory books?
Nt: The day I heard I was HIV – Everything changed!
Nx: The day my grandmother passed away...



Nv: My sickness...
X: I am going to tell about my childhood... It was my dream to play soccer and to go to school, but I can't make none of my dreams come true...



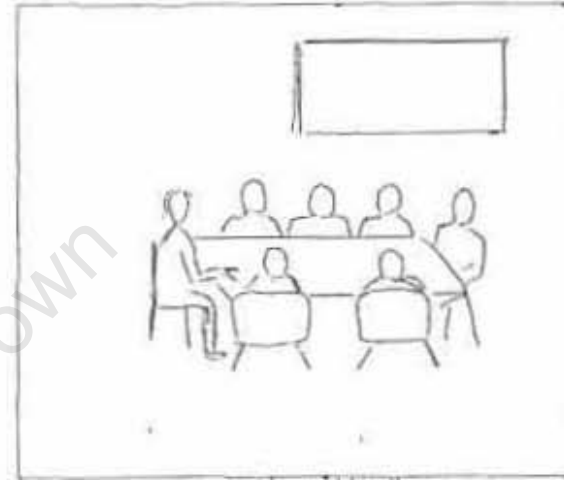
W: Tell me about your dreams
Nt and Nx: to have my own house
Nv: To have a car
X: To have a good job so I can make my family's dreams come true



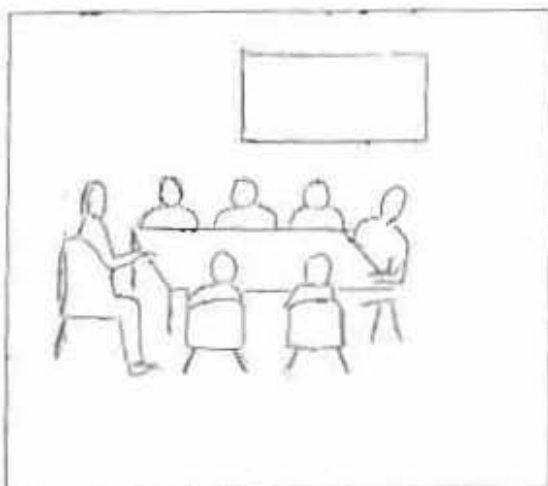
W: What makes you happy?
 Nv: My family...
 W: What makes you sad?
 X: To be without a job...



W: What makes you angry?
 X: When people talk behind my back.
 Nv: It makes me want to fight!



W: Why do you think I am asking these questions?
 X: You want to know about us!
 Nv: You want to know how we survive as Positive people.



W: Why do you think I want to know that?
 Nv: So that you can solve our problems?
 W: What did I say in the beginning?



W: I said that I don't have money and I am not coming here because I think I can solve your problems. I am here because I hope that together we can do something...



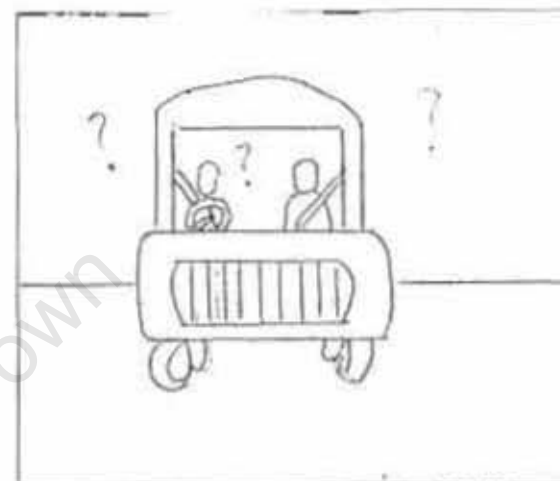
W: What do you feel about that? Do you think we can solve problems together?
 X: I think maybe we can. I am not sure though. We can't solve all problems, but maybe we can solve some together if we try!



X: The group decided we don't want to continue with the research
W: Why not?



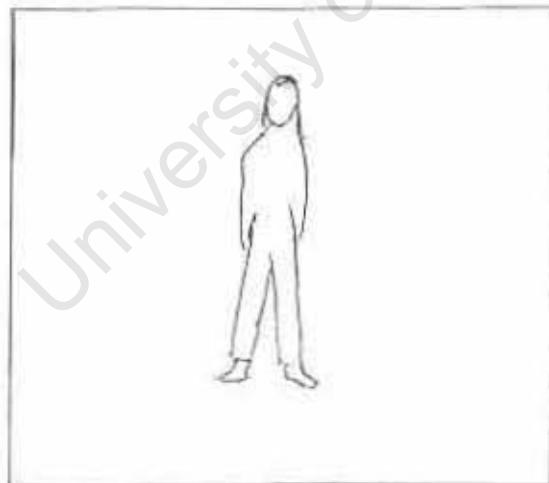
X: Nx and me are starting a job and we don't have time
W: And Nv?
Nv: I don't want to say!



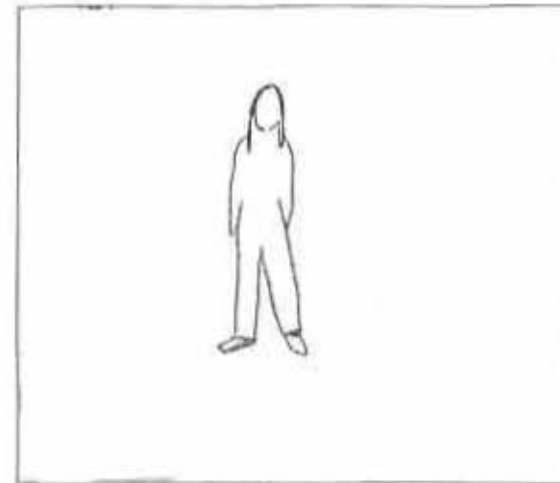
W: I am very sad B! I wish they would talk to me and tell me what went wrong!
B: I am also sad!
W: I wonder what should I do?



W: I know! I have to keep on doing research – We asked questions. Then we listened to the answers. So now I must think and plan what to do next



W: I have learnt a lot by listening to the tapes! I can see where I made mistakes and I have thought about how I can do things better.



W: We have done lots of good work here. I don't want it to go to waste! I must go back and tell them what I have found. Then we can decide what to do next! And this time I will learn from my mistakes and do things better!

Appendix C

Stages of Grieving

Elisabeth Kübler-Ross's (1969) book, "On death and dying" gives insight into the needs of people with terminal illnesses, and their families. Kübler-Ross interviewed people with terminal illnesses in order to learn more about how they came to terms with their impending death. In her book, she described 5 stages, which she observed the patients to experience in this process. These are: denial, anger, bargaining, depression and acceptance (the stages do not necessarily follow this order). Below a brief explanation of each of the stages is given, followed by some extracts from the transcriptions of the current study, which appear indicative of the stage described.

Denial

Kübler-Ross (1969) reports that most of the patients she interviewed reacted with shock and disbelief when they initially heard their diagnosis. Many of them could not believe that it could be happening to them and thought the doctor had made a mistake. Below are two examples from the transcriptions where the participants show evidence of denial.

L: (translated from **Xhosa**): I accepted it [HIV diagnosis] but there were times that I just think maybe the doctors.. ah...made a mistake. (LAUGHTER) But I got a lot of support from the support group when I say to them I'm HIV positive.

Nt: (translated from **Xhosa**); I did not accept it [HIV diagnosis] for one and a half year, until I told my husband ... and my husband did not accept it so I decided to accept it so that I can raise my children.

Anger

The denial stage is often followed by feelings of anger and resentment. The anger may be directed at other people, oneself or God (Kübler-Ross, 1969). In the quotation below, Nx expresses anger towards all males, possibly because she believes that it was a man who infected her with HIV.

Nx: (Eng) Me also.. The time I got the results I am HIV positive, I took the decision not to have a boyfriend again till now from 2001 till now. I just stay with my children. And when I see man even just walking around in the road, I hate him and I don't know why.

Bargaining

In this stage, the patient attempts to postpone the inevitable by bargaining with God or some higher power to allow him/her more time in return for promises of good behaviour or service to God etc. (Kübler-Ross, 1969). The quote given below may not necessarily indicate that the participant was bargaining with God, but the researcher thought that this could be the case.

Nx: (Eng) Me also.. The time I got the results I am HIV positive.. I decided to know now Jesus as my saviour. I must go to the church and praise God every time..

Depression

As the illness progresses and becomes harder to deny, the patient is filled with a great sense of loss. This loss may have many facets (e.g. the loss of one's body image, the loss of physical and/or financial independence and the loss of one's hopes and dreams for the future). Not all of these losses are necessarily immediate, but patients often experience depression in anticipating these losses (Kübler-Ross, 1969).

T (translating from *Xhosa* for Nt): Nt said that there is nothing that makes her happy. Everything changed, because she knows that any day she can die.

Acceptance

Kübler-Ross (1969) reports that patients who are given sufficient time and help to work through their anger and grief, come to a stage of acceptance of their impending death and a sense of peace. In the quotation given below, the participant indicates that he has come to an acceptance of his diagnosis, but this may be a form of denial.

X (Eng): There's no change on my side, I am still the same. I was not sick at all. I just want to protect me, get treatment.. use treatment

R (Eng): Are you worried about what might happen if.. when you do get sick? (Question is translated into *Xhosa*)

X (Eng): No, not at all because when I told my mother about this problem, she told me that anybody is going to die, not only people who are HIV, everyone is going to die. That's why I am still strong.

Appendix D

Hope and Despair

This appendix gives some examples of extracts which demonstrate the contrasting emotions of hope and despair which the participants described in the focus group sessions. (See 3.8.6 on page 56 for further explanation).

Hope

Extract 1 (GRP2)

Nx (Eng): Me..last month, in May I was very sick.. very sick and come to see this doctor. And he told me I've got pneumonia and my CD4 [count]¹ it was 147. It was very, very low. And the doctor told me they are going to start with the treatment. So they gave me the appointment - it was on the 6th of June, but the time I came back to them again.. my CD4 ..my CD4 now is 420 ...so they cancelled that treatment. So I'm always hoping that maybe I'm going to be alive till the government get a cure for us. I am going to stay alive...

..I was worried that time my CD4 was 147 and I was very very weak and I was worried, because I think maybe I'm going to be sick and, but now I feel very strong and healthy...very strong!

Extract 2 (GRP3)

Nx (Eng): I think it's [the memory box] very important to the people who are HIV because the people they didn't have a person to share some things. But if you do the memory book or box it's easy because you write down all your problems and the stress goes away, ja ..I was having a lot of problems. But the time I started the memory program, I was feeling very good.

¹ The CD4 count refers to the number of CD4+ T-lymphocyte cells per micro-litre of blood. The HIV virus attacks these cells and reduces the CD4 count, thus depleting the immune system and leaving the patient vulnerable to opportunistic infections. Once the count has gone below 200 it is considered to have reached a critical level and anti-retroviral therapy is often initiated if available (Lachman, 1999, American Association for Clinical Chemistry, 2005).

Extract 3 (GRP3)

Nv (Eng): The doctor told me that I'm HIV Positive and I will never walk again so he was going to give me a wheel chair. So they give me a wheel chair. I was worried about that I could never walk again...I was walking with crutches. Because I don't want to use the wheel chair!

R (Eng): So it's a story of victory?

Nv (Eng): Yes!

Despair**Extract 1 (GRP2)**

T (translating for Nt from Xhosa): Nt said that there is nothing that makes her happy. Everything changed, because she knows that any day she can die.

Extract 2 (GRP3)

Nt: (translated from Xhosa) That day [day of diagnosis with HIV] was different. It was like I was in another place. On that day it was not the same as the other days, and the sun seems dark. Everything was funny. Everything changed.... the world changed.... just everything changed!

Extract 3 (GRP3)

Nx (Eng): When you are sick it is as if your soul can't rest easily because my little daughter always used to sit beside to me and she don't want to play with the other children. I think sometimes that I won't even be able to pass away easily because she always look at me like this. It's very hard for her, she is crying when she looks at me. I just didn't feel any pain now I'm just thinking about her.

Extract 4 (GRP4)

X (Eng): To stay without a job, because I am not working anymore that makes me sad. I don't want to sit doing nothing, because I'm going to steal from the others (LAUGHTER) and then I'm going to jail if I rob the others ..Staying without a job is something that makes me sad. Also think about every day, think about why I can't get a job.

Appendix E

The Researcher's Questions

Below the main questions used by the researcher in GRP1-5 are listed. (Questions from GRP7 and 8 are not listed as these sessions were mainly excluded from the analysis process, because of the poor quality of the tapes).

Group Number	Phase	Question
GRP1	Preparation	What do you think research is? Can anyone describe what it is?
GRP1	Preparation	Who do you think does research?
GRP1	Preparation	What skills do you think you have that you can use in this research process?
GRP1	Preparation	How do you feel about doing this research? What do you think about doing research like this?
GRP1	Preparation	What things do you think it's important that we agree upon together, in order to work well together? <i>(This question was used to initiate discussion on the group contract).</i>
GRP2	Investigation	Where are you now? What are your lives like now?
GRP2	Investigation	Can you tell me about what things there are then that are good in your lives? Things that are good for you, that you are happy about?
GRP2	Investigation	What is it like in this community? Are the people accepting of HIV [positive people]? How do they respond when they find out someone is HIV [positive]?
GRP2	Investigation	How do you feel about being HIV [positive]?
GRP2	Investigation	Are you worried about what might happen when you do get sick?
GRP2	Investigation	You have spoken a little bit about death. Do you think about death a lot?
GRP2	Investigation	Are there things that give you hope at the moment in your life?
GRP3	Investigation	Can you tell me how you have found making memory boxes so far, what has it been like for you?

Group Number	Phase	Question
GRP3	Investigation	Perhaps you could tell me about....if you feel comfortable to tell me about a page that has been particularly helpful for you..
GRP3	Investigation	What dreams do you have?
GRP4	Investigation	What makes you happy?
GRP4	Investigation	What makes you sad?
GRP4	Investigation	Are there things that make you angry?
GRP4	Investigation	If you were to describe yourself to somebody, how would you describe yourself?
GRP4	Action	I want you to start thinking about what problem you would like to work on...Perhaps you can think about what you would like to see changed....it could be...something in your own life, something in your family or something in the community....
GRP5	Investigation and Action	<i>In this group, no new lines of questioning were initiated. Instead the researcher asked some questions to clarify with the participants about what they had said previously and also repeated some questions that had not been fully addressed in the previous groups.</i>

Appendix F

The Research Process

In this appendix, additional information about the research process and each of the focus groups is given. Information that is given in the main body of this document has either not been repeated or has been mentioned briefly.

The first meeting in which informed consent was taken (GRP0)

Date: 5/12/2003 Research Phase: Preparation Attendance: Nx, Nv, Nt, L and X

At this meeting, the researcher gave the participants information about the research and gave them the opportunity to ask questions. The participants then gave their consent to take part in the study.

Focus group meeting 1 (GRP1)

Date: 12/6/2003 Research phase: Preparation Attendance: Nx, Nv, Nt, X, L
--

The researcher began this session by asking the participants what they knew about research. Through questioning them, she elicited the fact that they thought research was something done by outsiders to the community and that it would bring themselves and the community certain benefits. The participants also talked about their expectations for the research. The researcher then explained to the participants that PAR is different from other kinds of research as the participants are the experts in the study, not the researcher and that they have knowledge and skills to contribute to the process. She also explained that the research would involve asking questions and gathering knowledge and then using the knowledge gathered to form a plan of action aimed at solving problems. The researcher then asked the participants to draw up a

group contract. In the last part of the session, the researcher and the group members introduced themselves to each other by giving a short life history and asking each other questions. The outcomes of the session were as follows:

- The participants expressed their expectations
- A group contract was formed
- The participants and the researcher introduced themselves to each other

Focus group meeting 2 (GRP2)

Date: 19/6/2003

Research phase: Preparation and Investigation

Attendance: Nx, Nv, Nt, X, L

The main focus of this session was discussion of the participants' needs. The researcher tried to encourage group discussion, by instructing the participants to talk to each other in Xhosa. The idea was that the translator would summarise the main points of the discussion when there was a gap in the conversation. This did not work very well, as the conversation tended to peter out without the input of the facilitator, and so the group members went back to answering the researcher's questions one by one. The main outcomes of the session were as follows:

- The participants described their physical needs
- They also talked about some more abstract needs, such as, their experiences of rejection and the need for acceptance and support; and the need for hope.

Focus group meeting 3 (GRP3)

Date: 26/6/2003

Research phase: Investigation

Attendance: Nx, Nv, Nt, X (L was absent)

In this session, the participants started a spontaneous discussion in Xhosa around some of the points that were raised the previous week. This was the longest period of Interactive group discussion in the research process. The topics they discussed were: their experiences of rejection and their concerns for their children. Following this discussion, the researcher asked the participants to talk about their memory boxes. The participants all commented on how helpful the memory boxes had been to them and shared something they had written in their memory books. There was also a long discussion about how the participants felt about disclosing their status to other people and their fears of rejection. Towards the end of the session, the group spoke about their dreams. The outcomes of the session were:

- Discussion of the value of the memory boxes to the participants
- Sharing about themselves through reading what they had written in their memory books
- Start of discussion about their dreams

Focus group meeting 4 (GRP4)

Date: 3/7/2003

Research phase: Investigation and Action

Attendance: Nv and X (L, Nx, Nt were absent. Nt was in hospital)

This was quite a difficult group session. X and Nv were not all that talkative and thus it was a struggle, at times, to keep the discussion going. The discussion on dreams was continued from the previous week and then the researcher asked the participants to talk about what made them happy, sad, and angry. The idea behind these questions was to get an idea of what was really important to them. At the end of the session, the researcher reminded the participants that the plan was for them to work together on solving their problems. They expressed some uncertainty and reservation about this, but agreed to it. The researcher then asked the participants to think about what problem they would like to address as a group. The outcomes were as follows:

- Discussion about the participants' dreams
- Discussion on what makes the participants feel happy, sad and angry
- The researcher asked the participants to think about what problem they would like to address and they expressed doubt and uncertainty

Focus group meeting 5 (GRP5)

Date: 10/7/2003

Research phase: Investigation and Action

Attendance: L and X (Nv, Nx, Nt were absent. Nt was in hospital)

This meeting was also poorly attended. The researcher was concerned that there was a problem, which the participants were not telling her about. In this meeting, the researcher firstly summarised what had happened in the previous two meetings as L had not been at these and then used the opportunity to clarify some issues that had come up in the previous groups. The researcher then asked the participants what they would like to change either in their own lives, their families, or the community. The outcomes were as follows:

- Clarification of some issues
- Discussion about what the participants would like to change in their lives

Focus group meeting 6 (GRP6)

Date: 17/7/2003

Research phase: Action

Attendance: Nv and X (L, Nx, Nt were absent. Nt was in hospital)

At this meeting, X informed the researcher that all the participants wanted to withdraw from the research. (This meeting is described in more detail in Section 2.6.3 on page 21).

The Researcher Analysis Cycle

In this cycle, the researcher analysed the information gathered in Participant Cycle 1 and prepared feedback to give to the participants. This cycle is not described in detail as it did not involve the participants.

Focus group meeting 7 (GRP7)

Date: 24/2/2004

Research phase: Preparation and Investigation

Attendance: Nx, Nt, Nv, X (L could not be contacted at that time)

In this session, the researcher negotiated with the participants on whether they were prepared to participate in a second PAR cycle and the participants gave verbal consent. Feedback was then presented to the participants (this is described in Chapter 3).

Focus group meeting 8 (GRP8)

Date: 6/3/2004

Research phase: Investigation and Action

Attendance: Nx, Nt, X (Nv was working on that day and L could not be contacted)

In this session, the researcher asked the participants to reflect on the group process and give her feedback about their experiences. The participants were given R100 in recognition of their contribution to the process. (L and Nv were both contacted at a later stage and given R100. They were also given the notes from the sessions they had missed.)

Appendix G

Analysis Codes and Categories

This appendix gives more detail about how the researcher went about coding and categorising the data at the second and third levels of analysis. (The first level of analysis is not referred to as no coding and categorising took place at this level).

Second Level of Analysis

The main objective of the second level of analysis was to develop meaningful feedback to give the participants from their contributions in Participant Cycle 1. Hermanus et al. (2003) divided their empowerment interventions into those that strengthened either the participants' knowledge or attitudes or skills. The researcher thought that these three categories would make a simple and useful way of helping the participants understand the concept of empowerment and thus made use of them when developing feedback for the group. In the analysis process, the researcher coded extracts from the transcriptions according to the categories: knowledge, attitudes, skills and resources (resources was an extra category added by the researcher). These categories were then used to develop pictorial representations of the data in order to give the participants feedback. Table G.1 gives extracts from the transcriptions and shows how they were coded and categorised.

Third Level of Analysis

The third level of analysis involved analysing the research process. Thus the codes represent the processes and challenges that occurred in the research. For example, within the preparation phase, the researcher noted that the way the participants spoke about the research appeared to show that they expected to take a passive role in the research and they expected the researcher to take the active role. Sections of text that showed this were therefore coded "passive participant vs. active researcher". This code was later grouped together with other similar codes to form the category "defining roles". In Table G.2 some extracts from the transcriptions are given along with the codes and categories that were assigned to them.

Transcription extract	Context	Code assigned to extract	Category assigned to code
Nt (Translated from Xhosa): "I accepted it, but there were times that I just think maybe the doctors made a mistake..."	L's description of her reaction to her diagnosis as HIV positive	Attitude to HIV	Attitudes
Nx (Eng): "...since I was standing in front of the people I feel so brave and strong..."	How Nx felt when she disclosed her status to the whole community	Attitude to self	Attitudes
Nx: (Eng) "When you are sick it is as if your soul can't rest easy, because my little daughter always used to sit beside me... I think sometimes I won't even be able to pass away easily, because she always look at me like this... "	Nx's concern for her little daughter	Concern for family	Attitudes
Nt (Translated from Xhosa): "It is because every one is going to call me names, especially my family."	Nt's reason why she did not want to disclose her status to the community	Attitude to community	Attitudes
Nx (Eng): "They told us you must eat the right food. But where do you get the right food?"	Nx is talking about the group's needs	Knowledge re: HIV/AIDS	Knowledge
X (Eng): "Nv was reflecting my story and she gave me some strong words to encourage me..."	X is talking about the Memory Box Training and the skills that they were taught.	Interpersonal skills	Skills
T (translating from Xhosa for Nt): Nt is saying that the memory box is good for her, because she is not thinking about anything, she is writing everything down.	Nt is talking about how she has experienced the process of making her memory box	Memory Boxes	Resources

Table G.1: Second Level Codes and Categories

Transcription extract	Context	Code	Subcategory	Category
L (Eng): When you are coming here to ask us questions, when we answer you, what are you going to do with these answers?	R had just explained that research was about asking questions.	Passive participant vs. active researcher	Defining roles	Preparation phase
L (Eng): Me, I want you to take these answers like...there are many tourists at [UCT]. So if people want to know about this research.. so you must bring this tape cassette... to the tourists. And the tourists [they] know what they can do...	R had asked the group what they wanted her to do with the results.	Participant expectations	Addressing expectations	Preparation phase
Nv (Xhosa): Yes, it is like that...	Nx spoke about her anxiety for her children and Nv identified with what she was saying	Identification with other group members	Benefits of sharing in the group	Investigation phase
X (Eng): I think so, but I'm not sure...(LAUGHS). I can't say: 'Yes it can work', I can't say: 'No...'	R had asked X if he thought solving problems as a group would work.	Uncertainty about solving own problems - low self-efficacy?	Planning action	Action phase

Table G.2: Third Level Codes and Categories

Appendix H

Introduction to Participants

In this appendix, more details about each of the participants are given for the reader's interest. Some of the information is taken from informal discussions that the researcher had with the participants (which were recorded in the researcher's journal) and the rest of the information is from the transcriptions). Some details about the translator are also recorded here as the translator played a part in influencing the research process and thus her background is considered to be important for the reader's general information.

H.1 L (20 year old, single woman with no children)

Age (2003): 20
Birth Place: Orange Free State
Schooling: Left after Std 8 (Grade 10)
Marital status: Single
Diagnosed HIV +ve: February 2003
Children: none

L is an extremely friendly girl with a beautiful smile. At the age of 20, she was the youngest member of the group and one of the most outspoken (even though she did struggle with her English). In the first group she introduced herself in the following way:

Introduction to L

L (Eng): "My name is L. I was born in Orange Free State and my mother come from Butterworth. When I was young, I was staying with my grandmother in Orange Free State but as the time goes I decided to go to my parents in 1998 here in Cape Town. So I am coming here and then in 1999 my mother and my father divorced. So my mother go to Transkei and I go with my mother to Transkei to holiday. I come back to my father so when I come, I come back to my father, my father was changed. So I stay, but my father likes some girls too much. So I stay with my

grandmother. So when the time goes my grandmother died so I stay to my father. My father stay with other girlfriend and that girlfriend treat me funny. So if I tell my father, my father beat me. If my father drunk, he can't sleep at the home, so she told me I must phone my mother and tell her this problem. So my mother come to take my card but my father took the card and burn it in the fire, and so he told me I must go away, he doesn't want a dog in his home. So my mother go away and she got married again. So in 2001, I decided to go and look for my other family. I found my other family. So I stay with my sister's brother. So I stay with her and she takes me like I am her child. Because at that time I was suffering, my father takes all the clothes by me. So he started first to buy me the clothes. So she takes me like I am his child. I don't take it like I have a father like my father. So and my mother is married again so I don't take it I have parents. I take it she is like my parents. The time they tell me I am HIV, it was 14 February this year."

Reaction to Her HIV Status

L found out about her HIV status on the 14 of February 2003, just 4 months before this research project started. When the researcher asked her how she felt about being HIV positive she replied:

"I accepted it, but there were times that I just think maybe the doctors made a mistake. But I got a lot of support from the support group when I say to them I'm HIV positive." (translated from Xhosa)

Family Reaction

The very same day L found out about her HIV status, she told the family members with whom she was living. Initially they seemed to be accepting of this news, but over time, L found that their attitude towards her had changed and they were no longer happy to have her stay with them. L then went to stay with a friend. She has not told many other people about her status. She has told one of her sisters who lives in Butterworth and an aunt who is living in Khayelitsha. She has also told a few trusted friends. Since the events described above, L has been reconciled with both her parents and goes to visit them frequently. She also stays with her father at times, but she has not told either of her parents about her HIV status. She is afraid of their reaction to the news.

H.2 Nt (23 year old mother of 1)

Age (2003): 23

Birth Place: Balfour, Eastern Cape

Schooling: Left after Std 8 (Grade 10)

Marital status: Married

Diagnosed HIV +ve: April 2001 (5 months pregnant at the time)

Children: 2 (first 2 years old, living in Eastern Cape; 2nd died May 2003 at age of 9 months)

Nt Introduces Herself to the Researcher

Nt: (translated from **Xhosa**) [I] was born in Balfour, in the Eastern Cape. My name is Nt. I was born on the 5th of March 1980. At home, I was staying with my mother and my grandfather. My grandfather passed away. I studied in Balfour and when I passed Std 7 [I came] here to Khayelitsha. I left school because I had no means....I mean I was unable to continue my studies. I came from Khayelitsha to Masiphumelele and I met a husband here. I got married and I fell pregnant. When I was five months pregnant, on the 5th of April, I went to the Clinic and I was told that I'm HIV Positive.

I did not disclose to my husband, I kept it inside until I was ready. I fell pregnant again and in November I decided to tell my husband's family when my second born was seriously sick. They chased me away showing that they don't love me anymore but they did not say it in person, they were talking to other people. As my child was sick, I stayed in Groote Schuur [Hospital] for three months, and she passed away in May this year.

Before he [my husband] was not on my side. He discriminated against me, but now he is coming to visit sometimes. He likes listening to his family and he is not staying here any more, he is staying in Gansbaai. I am now staying alone.

Nt Describes Her Reaction to the News that She Is HIV Positive

Nt: (translated from **Xhosa**) I did not accept it for one and a half year, until I told my husband....and my husband did not accept it so I decided to accept it so that I can raise my children.

Nt: (translated from **Xhosa** by translator): Nt said that there is nothing that makes her happy. Everything changed, because she knows that any day she can die.

H.3 X (29 year old father of 2)

Age (2003): 29

Birth Place: Unknown

Schooling: Completed Grade 12 (Std 10)

Marital status: Single

Diagnosed HIV +ve: 2002

Children: 2 (the eldest, a girl of 7, is living in Eastern Cape; the youngest, a boy of 2, is in a children's home in Masiphumelele)

When the research process began, X had only been part of the group a short while. He came across as friendly and co-operative though quite reserved. Although he participated in all the discussions, he did not speak much about himself. In the first group, his introduction to himself was short and uninformative:

X (Eng): "I was born in East Cape, in Fort Beaufort. I came to Western Cape to look for a job. I stay here in Masiphumelele, I join this project, Memory Box.(SIGHS)..You can ask me questions..."(LAUGHTER)

Childhood

In GRP3, X read to the group from his Memory Book about his childhood:

"When I was young, I grew up in a poor family, it was a lot of brothers and sisters and we were depending on my grandmother's money. Sometimes I went to school without shoes and sometimes it was winter time and it was very cold and I must go to school. I try by all means, but at that time we were depending on my grandmother's pension money and she can't afford to buy for all of us a uniform. But I managed to be at secondary, where I choose to live at school and look for a job. Even if I want to play football I can't because I have no soccer boots. You can't play without soccer boots. My teammates tried to organize me soccer boots. I was very interested in football, but because of the situation I can't make none of my dreams come true - education and sport. So that is about my childhood."

Work

Just before the research started, X lost his job in the Navy where he had worked for five years. This was incredibly frustrating for him as he was the only person in the family with a regular income and was providing for his younger brothers and sisters as well as his children. In GRP4 he spoke about his frustration:

X (Eng): "...To stay without a job, because I am not working anymore that makes me sad. I don't want to sit doing nothing, because I'm going to steal from the others (LAUGHTER) and then I'm going to jail if I rob the others ...Staying without a job is something that makes me sad. Also think about every day, think about why I can't get a job."

H.4 Nv (30 year old mother of 1)

Age (2003): 30
Birth Place: Butterworth
Schooling: Grade 10 (Std 8)
Marital status: Single
Diagnosed HIV +ve: 2001
Children: 1 (a girl of 7 who lives with Nv)

The first thing that struck the researcher about Nv was her laugh. While everything else about her is quiet and unobtrusive, Nv's laugh is loud and attention-grabbing. She was one of the least talkative in the group. Nv struggled with her English and mostly spoke in Xhosa. When she was asked to introduce herself, she was very brief:

"I was born in the Eastern Cape, Butterworth. I have one child [a 7 year old girl]. I'm staying here in Masiphumelele. I was diagnosed HIV in 2001. I was very sick. I was unable to walk. I was sleeping in bed, but now everything is better. The Doctor told me that I won't walk again. He was going to give me a wheel chair." (translated from Xhosa)

"My Sickness"

The subject of her sickness was the one topic on which Nv was prepared to talk at length. In GRP3, She read the following to the group from her memory book:

Nv: (Eng) "In 2001, I was admitted in Hospital. I could not walk and I was in pain. The nurses had to bring everything for me and do everything for me. I was isolated from other people. I was sleeping in my own room called a ward. Sometimes the nurses take me at 11AM and put me in the chair and I have sit on that chair until 5PM and they put me into the bed again. That was something I had to do every day. I was waiting for the results of the doctor. So I was staying there without any pain killers. I told the doctor about my pain, but he didn't give me nothing for the pain. He came late to tell me about the results. The doctor told me that I'm HIV Positive and I will never walk again so he was going to give me a wheel chair. So they give me a wheel chair. I was worried about that I could never walk again."

Having overcoming her illness, is a great source of pride for Nv. She did not accept the doctors prediction that she would never walk again and she refused to use the wheel chair. Instead she used crutches until she was able to walk on her own once again.

Family Reaction

In contrast to most of the other group members, Nv reports that her family was very supportive of her. She has a number of brothers and sisters, here and in the Eastern Cape. She recalls the day she found about her HIV status:

"I cried, I was also sad, I didn't want even to talk that day, they helped me at home saying I mustn't worry about that like when I hear about it there was no one funny." (translated from Xhosa)

H.5 Nx (40 year old mother of 3)

Age (2003): 40
Birth Place: Cape Town
Schooling: Grade 9 (Std 7)
Marital status: Single
Diagnosed HIV +ve: 2002
Children: 3 (boy of 21; girl of 19; girl of 8 - all 3 live at home with Nx)

Nx was the most enthusiastic and talkative member of the group. She was the oldest member of the group and the only one with grown-up children.

Nx: (Eng): "I was born here in Cape Town. It was in 1963 and my mother, she's a coloured woman, but the last time I saw her I was five years old. My father took me to Transkei to my grandmother and I grew up with my grandmother in Transkei. My father also married another woman. It was the time, I lost my school, looking after the children at home, cooking everything. So when I was 17 years, I came back to Cape Town to look for a job and I've got a big boy called B. He was born in 1982, he is 21 years now and I've got a daughter also, she is nineteen. She is doing Standard eight here in Masiphumelele and a little girl, she is eight. Her name is W. And I'm staying on the other side, because the time when I told my family that I'm HIV, they chased me away and my children. And I was renting a small house on the other side and I am staying with my children. But I am just happy staying with my children - no problem. Just looking after my health and my children's future."

Reaction to Her HIV Status

In 2001 Nx was diagnosed as being HIV positive. She recalls that her first reaction to the news was fear for the sake of her children:

Nx: (Eng) "...so the time I heard my results and they told me I'm HIV, I was looking at my children and I was worried because I know that it is very difficult to grow up without your mother..."

Family Reaction

Nx's family, her step-mother, in particular, reacted very negatively to the news of her HIV status:

Nx: (Eng): "When I told them at home, they did not accept me, they just take me as a prisoner just treat me as a prisoner at home, it was very, very hard..."

H.6 Translator (34 year old single woman with no children)

The Translator introduced herself to the group as follows:

T (Eng): "I was born in Umtata in 1969. I had one brother, no sisters. I was raised by my mother, but mostly by my grandmother....When I was doing Std 7 I fell pregnant. It was in 1986 and that time my parents were already separated from 1985 and I was staying with my grandmother.... In July the same year I gave birth to a beautiful daughter and when my baby was eight months she passed away. By that time my mother was here in Cape Town working, my father in Johannesburg and my brother was a Police in East London. In 1986 and 1987 I didn't go to school and In 1987 I went to school again. The situation was bad after my parents got separated because my father did not give us money to go to school so it was very bad. Okay, after my baby passed away, I came here to my mother and I continued my studies - Stds 8 and 9. It was not easy because my mother was working [only] three days [a week]... In 1996 my brother passed away. He was shot by his friend.... My father started being sick in 2000, very sick and last year he passed away. I started being sick in 1999. The whole '99 I was sick going in and out hospitals and in 2000, when I was sleeping in Tygerberg Hospital, the doctors told me to do HIV test. They said that it must be HIV that make me so sick, so I refused to do the test, but after some time I agree to be tested. I did the test and the results came positive in July. I did not tell my mother and I did not know what to do. I was like in another world. In 2001, I decided to disclose to my mother because I never stop being sick... She gave me a lot of support and I also told my other cousins here in Cape Town - not the whole family. But now I'm better. I joined the Memory Box Project last year. That's all about me."

Appendix I

Summary of the Participants' Needs

This appendix gives a summary of the participants' needs. In the table below, the need is presented in the left hand column and an extract is given from the transcriptions in which that need is expressed, in the right hand column.

Need	GRP	Quote
Better living conditions	GRP1	T: (translation of group discussion in Xhosa) So they are saying we wish we could get better places to stay and we wish that our environment could be improved, because the place we are living in is also dirty so we can get sick easily.
Good food to keep themselves healthy		Nx (Eng):....Other people have also got the problem. They didn't work... maybe they don't have the money for something to eat. They told us you must eat the right food. But where do you get the right food?
Work and more income	GRP3:	X (Eng): I want a good job...A good job will get me more money, because you don't have money to buy anything with the money we get now. It is a little money.
To provide for children and family	GRP2	Nx (Eng): ..I was so sad...the time I heard my results and they told me I'm HIV, I was looking at my children and I was worried, because I know it is difficult to grow up without your mother....even now I always pray God to say to him please can you just...protect me till my children are old....I want them to go to school to..at least to pass Std 10

Need	GRP	Quote
Rejection and the need for acceptance from others	GRP1	Nt (Translated from Xhosa):...I decided to tell my husband's family [re: HIV status] when my second born was seriously sick. They chase me away showing that they don't love me anymore. <i>(The participants did not actually put their need for acceptance into words, but it was evident from the way they spoke about their experiences of rejection that these had been very painful for them and they were longing for more acceptance from the community. See Appendix H on page 118 for more examples of the participants' experiences of rejection.)</i>
Despair and the need for hope	GRP2	T: (translating from Xhosa for Nt): Nt said that there is nothing that makes her happy. Everything changed, because she knows that any day she can die. <i>(The participants did not verbalise their need for hope specifically, but from the way they spoke about their experiences of hope and despair, it appears that they had a strong need for anything that would give them hope. See Appendix D on page 107 for further examples of the participants' feelings of hope and despair.)</i>

Appendix J

Group Contract

This appendix contains a summary of the group contract terms, which the participants drew up.

In the table below:

- The first column gives the name of the participant who suggested the contract term
- The second column gives the subject of the contract term e.g. participant relationships
- The third column gives the contract term (it includes the participants' actual words in quotation marks and, in italics, the way in which the terms were recorded on the contract).

Participant	Subject	Contract terms
Nx	Participant relationships	"understand each other" (Eng) <i>(Recorded as: Be understanding and sympathetic towards each other)</i>
Nx	Participant relationships	"respect each other" (Eng) <i>(Recorded as: Respect each other)</i>
L	Participant relationships	"advise each other" (<i>R asked for clarification, which is given below</i>) "..they have to ask me what bothers me or what's the problem...Or maybe Nx has something funny, so I must not laugh at Nx. I must just say: 'Nx you have this and you have to do this'" (translated from Xhosa) <i>(Recorded as "Care for each other")</i>
Nx	Conflict management	"...I think it's very important, when I got a problem and didn't understand to you as a researcher, I think the best way to come...and talk to you. Not talking at the back of you. Just come and sit and say to you: "R, I have got a problem like this and this," and we can solve it as a group. Not just talking behind you..." (Eng) <i>(Recorded as: Be honest and open. Bring any problems to the group)</i>

Participant	Subject	Contract terms
R	Confidentiality	<p>"..can we agree as a group that we won't talk about what we talk about here in the group, outside of the group?...by that I don't mean if we talk about research skills that you can't tell someone outside the group about that, but it's about the things that are...the important things... the private things." (Eng)</p> <p><i>(Recorded as: Do not talk about other people's private business outside the group)</i></p>
Group	Withdrawal of a member	<p>"..if someone wants to withdraw with any problem, they will let her, but they will first ask: what is the problem? If the person's problem is amongst us, we are going to talk about it and try to solve it, but if it is outside we will then let her go..." (translated from group discussion in Xhosa)</p> <p><i>(Recorded as: If someone wants to withdraw, the group will ask him/her what the problem is. If it is a group problem, the group will try to solve it. If it is an outside problem, they will allow the person leave.)</i></p>
Group	Absenteeism	<p>"They say it's going to be fine for the group, if someone like misses three meetings..They say if a person gave a report what makes her to be absent...like being in hospital maybe...they will be able to go back to her and tell her what was going on in the last stage..." (translated from Xhosa discussion)</p> <p><i>(Recorded as: The group will take responsibility for keeping anyone who misses a session up-to-date with what has happened.)</i></p>
R	Contract is open-ended	<p>"That's an important point...our contract, we can update, if something happens and then we decide okay, now we need to change it or we need to add something than we can do that..." (Eng)</p> <p><i>(Recorded as: The group contract can be changed or added to if the group decides it is necessary)</i></p>

Appendix K

The Therapeutic Value of the Group Discussion

In this appendix, extracts are presented from transcriptions which show the therapeutic value of the group discussions. (See 3.5.1 on page 42 for further explanation of this concept).

Finding Out that Others Have Had Similar Experiences

Bloch and Crouch (1985) assert that it can be encouraging for group members to discover that other people have similar problems to themselves as this can help them to feel less isolated. Below some extracts from the transcriptions are given in which the participants identify with each other's experiences.

Extract 1: (GRP3)

NX: When you are sick it is as if your soul can't rest easily because my little daughter always used to sit beside to me and she don't want to play with the other children. I think sometimes that I won't even be able to pass away easily because she always look at me like this. It's very hard for her, she is crying when she looks at me.....I just didn't feel any pain now I'm just thinking about her. (Eng)

NV: Yes it's like that. (Xhosa- not translated)

Extract 2: (GRP3)

Nt: SPEAKS IN XHOSA

T: (translating from Xhosa for Nt) That day was different. It was like I was in another place. On that day it was not the same as the other days, and the sun seems dark everything was funny.... Everything changed, the world changed, just everything changed.

X: I agree with her because when you hear something bad you feel like even the world is funny.
(Xhosa- not translated)

Sharing positive experiences

Some group members also shared some of their positive experiences and times in which they had overcome difficult circumstances. Hearing about the successes of other people who are in similar circumstances to themselves might have been a positive factor for other group members and have given them hope that they will also be able to overcome their difficulties (compare with Garvin, 1997).

Extract 1: (GRP2)

Nx (Eng): Me..last month, in May I was very sick.. very sick and come to see this doctor. And he told me I've got pneumonia and my CD4¹ was 147. It was very very low. And the doctor told me they are going to start with the treatment. So they gave me the appointment - it was on the 6th of June, but the time I came back to them again.. my CD4 ..my CD4 now is 420 so they cancelled that treatment. So I'm always hoping that may be I'm going to be alive till the government get a cure for us.

R (Eng): So you have hope?

Nx (Eng): Yes I have hope always. Because I was worried that time my cd4 was 147 and I was very very weak and I was worried, because I think maybe I'm going to be sick and, but now I feel very strong and healthy...very strong!

Extract 2: (GRP3)

NX (Eng): It is better to tell them than for them to find out for themselves, they laugh at you. The time I disclosed to the community the time I was sick they were gossiping saying, saying maybe she's HIV. I was so pale and they were laughing and saying look she is HIV and she don't want to tell us but the day I stand in front of the community they just shut their mouths. They just come to hug me and say you are a brave girl. They said: Its not easy to stand in front and tell the people about this virus, but you was very very strong and It was a miracle to the community because there are a lot of people here in Mph suffering of this virus but they don't want to talk about it, so they supported me a lot. Nobody laughing at me now because they know I'm HIV and I told them!

¹ The CD4 count refers to the number of CD4+ T-lymphocyte cells per micro-litre of blood. The HIV virus attacks these cells and reduces the CD4 count, thus depleting the immune system and leaving the patient vulnerable to opportunistic infections. Once the count has gone below 200 it is considered to have reached a critical level and anti-retroviral therapy is often initiated if available (Lachman, 1999, American Association for Clinical Chemistry, 2005).

Extract 3: (GRP3)

NV (Eng): Yes I'm going to read it. (READS FROM MEMORY BOOK) In 2001 I was admitted in Hospital, I could not walk and I was in pain. The nurses had to bring everything for me and do everything for me. I was isolated from other people I was sleeping in my own room called a ward. Sometimes the nurses take me at 11AM and put me in the chair and I have sit on that chair until 5PM and they put me into the bed again, that was something I had to do every day. I was waiting for the results of the doctor. So I was staying there without any pain killers. I told the doctor about my pain but he didn't give me nothing for the pain. He came late to tell me about the results. The doctor told me that I'm HIV Positive and I will never walk again so he was going to give me a wheel chair. So they give me a wheel chair. I was worried about that I could never walk again.

R (Eng): So it was a long time that you were sick?

NV (Eng): Yes, I was walking with crutches. Because I don't want to use the wheel chair!

R (Eng) : So it's a story of victory?

NV (Eng): Yes.

Appendix L

Group Discussion Extract

For most of the group sessions the participants spoke mainly to the researcher and thus there was not much interactive group discussion. However, there were some passages of group discussion. Below an extract from GRP3 is given, where some interactive group discussion took place spontaneously, in response to some points raised by the researcher when summarising the discussion from the previous week. This extract records the longest passage of interactive group discussion. In it, the group members discuss subjects like their experiences of rejection and their concerns for their children.

Extract from GRP3

R (Eng): Some of you said that you were sad about finding out about the HIV.

Nt: I was not sad but I cried. (Xhosa- not translated)

Nx: You cried? But definitely you were also sad.(Xhosa- not translated)

Nx (Eng): Nt is saying that she cried, but she was not sad (translates for R)

Nv: When did you become strong?(Xhosa- not translated)

Nt: After some time.(Xhosa- not translated)

Nv: I cried I was also sad, I didn't want even to talk that day. They helped me at home saying I mustn't worry about that, like when I hear about it there was no one funny.(Xhosa- not translated)

Nx (Eng): When I told them at home, they did not accept me. They just take me as a prisoner, just treat me as a prisoner at home! It was very, very hard....it was a hard time.

X: Who treated you like that?(Xhosa- not translated)

Nx: It was my stepmother.(Xhosa- not translated)

X: There is another guy, he is being chased away. He has got his own plate, spoon and even a jug to drink water, everything is separated. We, as his friends, wanted to talk to his parents, but they were not there. (Xhosa- not translated)

Nv: How long did he know about his status? (Xhosa- not translated)

X: Long time in 1995. (Xhosa- not translated)

(EVERYONE): Yhu-u! Why didn't they accept him for so long? (Xhosa- not translated)

Nx (Eng): X is saying this guy knows about HIV from '95. The family does not accept him, they don't want to share with him anything. (translates for the researcher)

Nv: Suppose there is someone who is already infected in his family? It's long time he is being positive. (Xhosa- not translated)

X: Everything he is using is only used by him only, and he is still young. (Xhosa- not translated)

Nv: Oh! I thank my family they didn't do that to me. (Xhosa- not translated)

X: I also think is the lack of knowledge from the parents, they did not understand. (Xhosa- not translated)

(EVERYONE SPEAKING AT ONCE in Xhosa- not translated)

R: Some of the other things you said was um.. worry about children.

Nx: Ja. (Talking in Xhosa)

Nx (Eng): When you are sick, it is as if your soul can't rest easily because my little daughter always used to sit beside to me and she don't want to play with the other children. I think sometimes that I won't even be able to pass away easily because she always look at me like this. It's very hard for her, she is crying when she looks at me.

Nx: I just didn't feel any pain now, I'm just thinking about her. (Xhosa- not translated)

Nv: Yes it's like that. (Xhosa- not translated)

R: Does she know about the HIV? does she understand?

Nx (Eng): Yes, she knows everything.

Nv: Does she know? (Xhosa- not translated)

Nx: Yes she knows. (Xhosa- not translated)

Nv: Didn't she always ask questions? (Xhosa- not translated)

Nx (Eng): No, she knows. That's why she thinks I'm going to die. She thinks that mummy is going to die soon. That's why, when I'm coughing, she used to say, "Mummy, I don't want to go and play with other kids. I'm going to look after you." She gives me tea and water and everything.

Nv: I remember the last born at home, she used to say, "My aunt, I'm going to play now. Call me if you need anything, but I'm going to play now." She play and she come and ask, "You don't need anything? When you finish washing I'm going to take your washing rags and hang them." Oh! I miss her so much! (Xhosa- not translated)

Appendix M

Laughter: Judgemental and Non-judgemental

This appendix gives some examples of where the group members laughed during the focus group discussion. The first section gives extracts where the laughter appears to be judgemental and therefore may have had a negative impact on the building of “safe space” in the group, and the second section gives examples of non-judgemental laughter, which appears to have had a positive effect on the group process (see Section 3.4.4 on page 40 for further explanation).

Judgemental laughter

Extract 1 (GRP1)

(Context: X introduced himself to the group and then the other group members started asking him questions about himself and his family)

T (Eng): Where is the mother [of your children]?

X (Eng): The other one's mother is in Eastern Cape

T(Eng): Different mothers?

X (Eng): Yes, different mothers

T: LAUGHS

(The researcher spoke to the translator about this incident before the next group session and asked her to be careful about laughing at the participants' comments)

Extract 2 (GRP2)

R (Eng): How do you feel about being HIV [positive]?

L (translated from **Xhosa**) I accepted it but there were times that I just think maybe the doctors made a mistake. (LAUGHTER) But I got a lot of support from the support group when I say to them I'm HIV positive.

Non-judgemental laughter

Extract 1 (GRP1)

R (Eng): And then we also said: Who does research? ...We said: people from overseas. Okay so that's what we said. But we've already discovered that that is possibly not true! I'm not from overseas! I'm from here. (LAUGHTER)

T: translates into **Xhosa**

L (Eng): Like you say you are from Cape Town, but you don't know Masiphumelele. So you are a visitor in Masiphumelele (LAUGHTER)

Extract 2 (GRP4)

X: I am a shy guy. I don't like to talk....

X: SPEAKS IN **XHOSA** (LAUGHTER)

T: (translating for X) Sometimes he drinks his beers and start talking. (LAUGHTER)

R: So that's what we must do! Bring some beer and then you will talk! (LAUGHTER)

Appendix N

Participation Table

The table given below shows the level of participation of each group member in GRP1-5, as well as their total level of participation in all five sessions (GRP7 and 8 are not included as the sound quality of the tapes made the level of participation difficult to determine). The percentages in the column "Total(All)" were derived by taking the total number of words spoken by each participant in each session and dividing by the total number of words spoken by all the group members and the researcher in the session (the translator's words are excluded). The column labelled "Total (Participants)" shows the percentage of words spoken by each group member out of the total number of words spoken by just the group members (i.e. excluding the researcher's words). (The word count includes all the words that were transcribed from the tape. Both the English words spoken and the Xhosa words that were translated into English on the transcriptions, were counted).

Participant	Total (All)	Total (Participants)	GRP1	GRP2	GRP3	GRP4	GRP5
R	57%	-	60%	54%	41%	72%	57%
Nx	15%	34%	15%	26%	32%	absent	absent
X	12%	28%	5%	9%	15%	20%	13%
L	10%	22%	12%	6%	absent	absent	30%
Nv	5%	10%	3%	2%	9%	8%	absent
Nt	2%	5%	5%	2%	3%	absent	absent

Appendix O

Participants' Words relating to the Concept of being Strong

This appendix gives extracts from the transcriptions where the participants used the word "strong". As pointed out in Section 3.8.1 on page 49, the participants used the word strong to describe both emotional/ psychological strength and physical strength (which was related to overcoming AIDS-related illnesses). The participants' use of the word "strong" seems to indicate that this idea is similar to the concept of empowerment (see Section 3.8.1 on page 49 for further explanation).

"advice...to make me strong"

In the extract (from GRP1) below, Nx speaks about what she wants from the research process.

Nx (Eng): But on my side, it's not about money just for the advices and the support. I need a lot of support because I know what I need. I am not talking about money. I am not wanting a lot of money. I am need your advice just supporting me to make me strong.

"That's why I am still strong"

The extract (from GRP2) below, comes from a discussion about the participants' needs. X was asked if he was worried about getting sick in the future and this was his reply:

X (Eng): No, not at all because when I told my mother about this problem she told me that anybody is going to die, not only people who are HIV, everyone is going to die. That's why I am still strong.

"Now I feel very strong"

In the extract (from GRP2) below, Nx describes her recovery from illness and how that gave her strength and hope.

Nx (Eng): Me..last month, in May I was very sick.. very sick and come to see this doctor. And he told me I've got pneumonia and my CD4 [count]¹ was 147.... but the time I came back to them again... my CD4 now is 420....(GASPS FROM THE GROUP).... So I'm always hoping that maybe I'm going to be alive till the government get a cure for us. I am going to stay alive

Nx: (Eng)I was worried that time my CD4 was 147 and I was very, very weak and I was worried, because I think maybe I'm going to be sick, but now I feel very strong and healthy...very strong!

"she gave me strong words to encourage me"

In the passage (from GRP5) below, X speaks about the value of the Memory Box process and the experience they had had of telling their stories to one another and giving each other feedback.

X: (Eng) NV was reflecting my story and she gave me some strong words to encourage me.

¹ The CD4 count refers to the number of CD4+ T-lymphocyte cells per micro-litre of blood. The HIV virus attacks these cells and reduces the CD4 count, thus depleting the immune system and leaving the patient vulnerable to opportunistic infections. Once the count has gone below 200 it is considered to have reached a critical level and anti-retroviral therapy is often initiated if available (Lachman, 1999, American Association for Clinical Chemistry, 2005).